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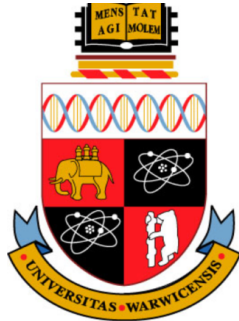
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**When “being with” becomes “caring for”:
Exploring the informal male carers’ experiences of
caring for those with cancer and /or dementia**

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Thesis submitted for the degree of Doctor of Philosophy

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Table of Contents

1. Background	12
1.1 Caring for those with Cancer	14
1.2 Caring for those with Dementia	17
1.3 Carers	19
1.4 Phenomenology	22
2. Rationale for Study	24
3. Systematic Review	26
3.1 Definition of informal carer	27
3.2 Search strategy	27
3.3 Results of Systematic Review	33
3.4 Research Question	50
4. Methodology	51
5. Pilot study	59
5.1 Pilot Study Question	60
5.2 Methods	60
5.2.1 Inclusion Criteria	60
5.2.2 Exclusion Criteria	60
5.2.3 Sampling strategy	60
5.2.4 Data collection	61
5.2.5 Ethical Considerations	62
5.2.4 Data Analysis	63

5.3 Findings of pilot study.....	64
5.3.1 Emerging themes.....	65
5.4 Discussion.....	72
5.5 Limitations of the pilot study	74
5.6 Conclusion	74
6. Rationale for Main Study.....	75
7. Main Study Male Carer Experience (MaCE)	76
7.1Research Question.....	76
7.2 Methodology.....	77
7.2.1 Inclusion criteria	77
7.2.2 Exclusion Criteria	77
7.2.3 Consent Procedure	77
7.2.4 Sampling strategy	78
7.2.5 Data collection.....	79
7.3 Data Analysis.....	79
7.4 Data Management and Patient Confidentiality.....	81
7.5 Ethical Considerations.....	81
7.6 Confidentiality	82
7.7 Anonymity	82
8. Findings.....	82
8.1 Sample Characteristics.....	83

8.2 Emerging Themes	85
8.3 Subordinate Themes.....	87
8.4 Superordinate Themes.	90
8.4.1 When ‘being with’ becomes ‘caring for’	91
8.4.2 ‘A sense of self’	104
8.4.3 ‘Being separate together’	112
8.4.4 ‘Connecting friendship with support’	122
8.5 Developing Understanding of the Findings.....	131
9. Literature Review following findings.....	135
10. Discussion.....	139
10.1 When ‘being with’ becomes ‘caring for’	140
10.1.1 Marriage.....	140
10.1.2 Gender	145
10.2 A ‘Sense of self’	154
10.2.1 Changing Self.	160
10.2.2 Maintaining self.	162
10.2.3 Self as spouse.	164
10.2.4 Transitions	167
10.3 “Being separate together”	170
10.3.1 Couplehood	171
10.3.2 Connection.	174

10.3.3 Isolation and loneliness.	176
10.3.4 Poems.....	181
10.4 ‘Connecting friendship with support’.....	183
11 Conclusion	188
12 Challenges and Limitations of the Study	190
13 Recommendations for Health and Social Care Professionals	194
14. Implications for Future Research.....	198
15. References.....	199
Appendices.....	214
Appendix 1 Systematic Review	215
Appendix 2 Ethics Letter Pilot Study	224
Appendix 3 Pilot Study Information Sheet	228
Appendix 4 Pilot Study Consent form	230
Appendix 5 Pilot Study Reply Slip.	231
Appendix 6 Ethics Letter Main Study	232
Appendix 7 MaCE Study Consent Form	236
Appendix 8 Interview Schedule- Cancer.....	237
Appendix 9 Interview Schedule- Dementia	239
Appendix 10 MaCE Information Sheet	241
Appendix 11 Emerging Themes (a)	244
Appendix 12 Example of Emerging Themes	245

Appendix 13 Subordinate Themes 246

Appendix 14 Superordinate Themes 247

Tables and Figures

Table 3.2.1	MESH Headings For Search Terms	27
Figure 3.2.1	PRISMA Flowchart	31
Table 5.3.1	Carer Characteristics In Pilot Study	61
Figure 5.3.1	Using The Audio Recorder	63
Figure 5.3.2	Emerging Themes From The Pilot Study	65
Table 8.1.1	Recruitment for MaCE	81
Table 8.1.2	Carer Profiles for MaCE	82
Figure 8.2.1	Emerging Themes (a)	85
Figure 8.2.2	Emerging Themes (b)	86
Table 8.3.1	Subordinate Themes	89
Figure 8.5.1	Self As Central To Experience	104
Table 9.1	Men and Marriage	136
Table 9.2	Men And Friendship/Support	138

Abbreviations

ACT	Acceptance and Commitment Therapy
Ahmed	Allied Health and Complementary Medicine
Assia	Applied Social Science Index and Abstracts
CASP	Critical Skills Appraisal Programme
CBS	Contextual Behavioural Science
Cinahl	Cumulative Index to Nursing and Allied Health Literature
GP	General Practitioner
GrayLit	Unpublished Research Network
HIV	Human Immunodeficiency Virus
IBSS	International Bibliography of Social Sciences
ICT	Information and Communication Technologies
IPA	Interpretive Phenomenological Analysis
MaCE	Male Carers Experience
MAGIC	Managing Access to Grey Literature Collections
MeSH	Medical Sub-Headings
NAO	National Audit Office
NCPC	National Council of Palliative Care
NHS	National Health Service
NHS REC	National Health Service Regional Ethics Committee
NICE	National Institute for Health and Clinical Excellence
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PsychInfo	Psychology Information
R&D	Research and Development
SCIE	Social Care Institute for Excellence
UK	United Kingdom
USA	United States of America

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Thank you.

Declaration

This thesis is submitted to the University of Warwick in support of my application for the degree of Doctor of Philosophy. It has been composed by myself, Rosemary Ann Horton-Smith, and has not been submitted in any previous application for any degree.

Rosemary Horton-Smith

Abstract

Background:

Social isolation and loneliness are found to be commonly experienced by informal carers, often elderly and already isolated by the demands of the caring role. There are 850,00 people with dementia in the UK, predicted to reach 2 million by 2051. In the UK, there are approximately 1.6 million people over 65 living with cancer, set to increase to 4.1million by 2040, which suggest that there may be a prolonged caring role for informal carers for those with cancer and/or dementia.

Aim:

The aim of the study is to examine the informal male carers' experience of social isolation and loneliness during caring at home for those with advancing cancer and/or dementia.

Research Question:

How does caring for someone at home with advanced cancer or dementia affect informal male carer experiences of changing social and personal relationships?

Methodology:

A qualitative approach using phenomenology was utilised. Semi-structured interviews with 9 male carers over 3 episodes were conducted. Interpretative phenomenological analysis (IPA) was applied to the data. A contextual behavioural science (CBS) model was applied to the findings.

Findings:

The overarching findings of this study which encapsulate the informal male carers experiences were: i) when 'being with' becomes 'caring for', ii) a sense of self, iii) 'being separate together', and iv) 'connecting friendship with support'. The CBS approach highlighted the process of change involved within caring.

Conclusions:

The men in this study identified difficulties in associating themselves with being either a husband or a carer. They are husbands first and foremost; caring changes their sense of self; caring changes their relationships for those they are caring for friends and family. These changes are experienced when 'being with' becomes caring for'. These findings have huge and immediate implications for policymakers.

1. Background

Being responsible for someone else's day to day needs, physical and/or emotional, may be something that some of us experience for a short or long period of time in our lives. Whether this is a choice or something that one feels compelled to do and how one adapts to that role, is explored in this thesis.

As society ages, more of our elderly population will need care as life expectancy increases, families become scattered geographically, and the implications of increased mortality in society becomes more evident (Hazra *et al.*, 2018). It is suggested that over the next twenty years, those over the age of 80 years will treble in number, and those over the age of 90 years will double in number in the UK. This rise in the elderly population has implications for society as a whole and for the National Health Service (NHS) (Windle *et al.*, 2011). In this climate of an increasingly elderly population, the need for more informal carers will increase as the economic cost of healthcare rises (Beach & McKenzie, 2014). In the last ten years, research has focused on the needs of the elderly as a specific subsection of society (Tilvis *et al.*, 2012; Victor & Yang, 2012). From this research, the issue of social isolation and loneliness has been widely reported. Social isolation and loneliness are different issues; the term social isolation is defined by the lack of or minimal interaction with others (Fine & Spencer, 2009), whilst the feelings of loneliness are a subjective response to this, sometimes described as emotional isolation in the literature (Dickens *et al.*, 2011). The prevention of social isolation and loneliness as experienced by our elderly population has been highlighted through research and policy (Windle *et al.*, 2011; Tomaszewski & Barnes, 2008; Victor *et al.*, 2002; Victor & Bowling, 2012; Fine & Spencer, 2009). The report

entitled “Dementia”. A NICE-SCIE guideline on supporting people with dementia and their carers’ in health and social care’, (Social Care Institute for Excellence-National Institute for Health and Clinical Excellence, 2007), identified that older people are vulnerable to social isolation due to the loss of friends and family, loss of mobility or loss of income. Findings from this report suggest that social isolation has an adverse effect on the elderly person’s health with social isolation being an important predictive factor for depression in this group. Earlier literature published examining the contribution that isolation and loneliness brings for those caring for the elderly (Beeson *et al.*, 2000; Robison *et al.*, 2009; Robinson-Whelen *et al.*, 2001) corroborate these findings. It can be argued that those who care for those in need are at risk themselves of social isolation and loneliness due to the demands of the role they take on. Tomaszewski and Barnes (2008) suggest that 6-13% of the UK population feel lonely ‘always’ or ‘often’. Their study highlights that elderly men are at greater risk of isolation and loneliness than their female counterparts, but is a subject the authors state but do not return to in the discussion of their findings. A further study suggests that if this figure is 10% of the population, the number of people that feel lonely could amount to 900,000 people in the UK (Tomaszewski & Barnes, 2008; Victor & Bowling, 2012).

In 2011, the Campaign to End Loneliness charity was set up to educate and inform society and professional groups to the extent of social isolation and loneliness within our society. The charity aims to end social isolation and loneliness through the promotion of valued connections in older age. Raising the awareness of this issue through political means and campaigns, information, and educational programmes, the charity hopes to encourage community

involvement in the prevention of social isolation and loneliness (Jopling, 2015; Broome, 2016). The Government report entitled “The Adult Social Care Outcome Framework 2017/18” (Department of Health, 2017) also sought to highlight this problem. The Department of Health surveyed its carers of those in need, with one question concerning the amount of social contact they had. However, the issue of social isolation, an objective measure of social contact, gives very little understanding on what importance or value that contact with others has for people and carers alike. Suggesting that loneliness is the subjective response or sadness to that contact or lack of contact, as defined by the English Oxford Living Dictionary 2018, requires in-depth analysis and research. To explore the meaning of social isolation and loneliness for those who experience it, may go some way in developing ways of helping and supporting those who are experiencing one or other. Age UK, the largest charity improving life for the elderly through information and advice, and media coverage of life for the older person (BBC1, When I Get Older 2012), both encourage the issue of isolation and loneliness to be given the exposure they demand. Enabling a conversation to be had around these sensitive topics will enhance our understanding of them, and in so doing, strive to improve the lived experience for carers.

1.1 Caring for those with Cancer

Cancer is the second most prevalent disease worldwide, with 17.5 million cases in 2015, and the predictions for the years ahead are that this is set to rise (Global Burden of Disease Cancer *et al.*, 2017). In the UK, 2.5 million people are living with cancer (Macmillan Cancer Support, 2017). Globally, the economic costs of care are spiraling and the numbers of those needing care, are increasing

(Jonsson *et al.*, 2016; Round *et al.*, 2015). This is predicted to have a huge impact on the National Health Service (NHS), and the demand for health and social care services (Public Health England, 2013; Etkind *et al.*, 2017). As society ages the numbers of those with cancer is set to rise. An increase in longevity also brings co-morbidities and the prevalence of multiple cancers in old age combined with other diverse diseases, increases the complexity of care needed. For informal carers this complexity of diagnoses, treatments, and prognosis can be exhausting (Farina *et al.*, 2017). As the condition of those with cancer changes, the focus of the informal carers experience changes also. For some carers now having to adjust to those with cancer approaching end of life, the demands of their caring role increases.

Over the last 45 years, palliative care services have been developed to address the needs of those at the end of life from cancer, from the opening of the first modern hospice at St. Christopher's in 1967, to the widespread specialist hospital and community services we have today. The emergence of expert pain and symptom management, psychological, social, and spiritual care ensures evidence based high quality of care for those who are dying (World Health Organisation, 2012). Whilst palliative care is well established with the hospice movement and the ongoing development of specialist palliative medicine to address symptom management, these services have hitherto been focused on those with a cancer diagnosis (Reinke *et al.*, 2008). Outreach services for patients and carers alike, provided by charities, for example, Marie Curie Care, Haven Trust, and various formal and informal carers' groups, offer support for carers at this time (Hudson & Payne, 2011). However, the carers experience of advancing

disease is not fully understood. The paucity of current literature on the carers experience of advancing disease hampers professional's evaluation of carers needs, knowledge of their caring experience, and delivery of timely and appropriate care.

One aspect of caring for those with advanced disease is end of life care. For carers caring for those at the end of life at home the practical aids and services needed to address physical caring are well highlighted in research (Cain *et al.*, 2004). The need for the economic resources, for example money to enable transport to and from hospital appointments, different foods that alleviate chemotherapy related symptoms, increased heating, and the work-care balance have also been addressed (Rowland *et al.*, 2017). However, the increased impending loss and grief pertinent to end of life care, adds to the already stressful role of informal and family carers (Hudson *et al.*, 2010). It has been suggested that carers needs are complex during their caring role, the need for information and education, practical help, psychosocial, and spiritual care, to name a few. The emotional needs of carers are seen as secondary to practical needs as identified by the carers themselves (Matthews *et al.*, 2004). End of life care is emotional and demanding and carer needs are changeable during this time and, as such, the support they need changes also (Morbey *et al.*, 2013). Flexibility is needed when supporting carers and the intervention of that support requires understanding and compassion. Caring for those at the end of life also brings questions for carers around their own mortality, a search for meaning in life, and a 'letting go' of the dying person (Rokach *et al.*, 2007). As it has been highlighted complex issues and emotions whilst caring for those at the end of life need to be understood to allow timely and appropriate care and support to be delivered.

Caring for those at the end of their life has been shown to be burdensome for the reasons above. The experience of the informal carer caring at the end of life needs to be examined in this light to ensure greater understanding by those who care for the carers and provide services to meet their needs.

1.2 Caring for those with Dementia

There are approximately 850,000 people with dementia in the UK (Prince *et al.*, 2014). Dementia affects all social groups and ethnicities, impacting on the family as a whole. It is suggested that someone may live with their dementia for 7-12 years on average, putting increasing physical and emotional strain on those caring for them (Alzheimer's Society UK, 2013). A report by Dementia UK, a lobby group for those with dementia and their carers', states that the number of people with dementia will increase to 1,700,000 by 2050 (Knapp & Prince, 2007) and for these people, their average life expectancy will be 4-5 years following diagnosis (National Council for Palliative Care, 2013). The difference in these two figures highlights the different approaches that organisations take. Those with dementia, as identified by the Alzheimer's Society, are living with their dementia and as such explains the numbers of years identified. The focus of the National Council for Palliative Care suggests a time frame when end of life is approaching for those with dementia. This protracted phase when complex care may be needed, highlights the different approaches by professionals but also the longevity of the caring role. These predictions, although differing, indicate that those with dementia will need care for many years as their disease progresses. The needs of this patient group will impact on all health care services and how care is delivered. Having identified that those with dementia are increasing in number,

the UK Government's Dementia Strategy (HM Government, 2008; Knapp & Prince, 2007) and the National Council of Palliative Care (2008), directed palliative care services to address the end of life care needs of those with dementia and those that care for them.

Analysis of the current research reveals that at present 63.5% of those who suffer dementia live at home (Knapp & Prince, 2007) suggesting that they are cared for by family or friends with intermittent health or social care services. These intermittent services focus on crisis management, for example after hospitalisation of either the carer or those with dementia, and are often short term. For those who choose to die at home, a reduction in the availability of funded care may put additional strain on those family members undertaking this role. This in turn will lead to more support being needed for those caring for those dying at home. Timing of palliative care intervention however, is difficult to assess in those with dementia as many of the symptoms may last for a prolonged period of time (Murray *et al.*, 2005a). An acknowledged pattern of a slow decline in abilities and cognitive function, as seen in those with dementia, suggests that a long period of care may be needed. Carers may experience a sustained role over many years; this pattern makes the introduction of palliative care difficult to assess and the timing of support at end of life, complex. The pattern of decline for those with cancer can be different, and the 'step style' changes seen in patient abilities and worsening symptoms are more indicative of an approaching end of life (Moens *et al.*, 2014; Coventry *et al.*, 2005). Symptom management at the end of life is crucial for patients and carers alike (van der Steen *et al.*, 2009) ensuring that both feel supported. The illness trajectories for those with cancer and/or dementia are very different as earlier research has highlighted. It is the purpose

of this research study to explore the experience of the informal carer in these two circumstances to increase understanding of their needs and to establish if there are differing needs from these groups. In my role as a clinical nurse specialist caring for those mainly with cancer, the incidence of those with dementia and cancer is increasing as are the numbers of patients and families with dementia who are referred to specialist palliative care services.

1.3 Carers

Carers fall into two categories, professional and informal. With the continued economic pressures on the NHS (McCaffrey *et al.*, 2015), society and professional service providers, are relying more heavily on family carers for those unable to care for themselves.

As the population ages, so will family carers age (Lloyd & Jessiman, 2014) highlighting that more support will be needed for them as a group to enable them to continue with their caring roles. Reports from the National Council of Palliative Care (NCPC), Alzheimer's Society, and National Audit Office (NAO), highlighted the importance of a carers' assessment to establish their needs (Dementia UK 2007, NCPC 2009, and NAO 2007). These reports acknowledged for the first time that the needs of carers should be addressed by services (HM Government, 2008), and that a holistic approach be taken to the care of those with cancer and /or dementia and their families. A further study from the Nuffield Council of Bioethics (2009) agreed that the carers' experience should be understood in more depth to improve the care for this group (Department of Health, 2010).

Further research on understanding the carers experience of advancing disease, for those with cancer and/or dementia, will identify how the needs of carers can be best met. According to Popay et al (1998), existing methods of exploring “lay knowledge or patient views” seen through professional methods of enquiry e.g. systematic reviews and quantitative research, are hampering our acceptance of the patient/carer expertise and skills needed to manage their caring role (Popay *et al.*, 1998). By utilizing consumer and user group experiences and working across disciplines to highlight divergent views and ideas, a greater understanding of carer experiences’ will be collated. These approaches justify and validate the need for continued in-depth research in to the carers experience in this case, advancing disease for those cared for at home.

Caring for someone at the end of life impacts on individual carer health (Robison *et al.*, 2009; Beeson *et al.*, 2000; Bramble *et al.*, 2009). These studies highlight the increased rates of depression, higher levels of stress, and increased experiences of loneliness and social isolation experienced by informal or family carers. Improved support for carers is likely to enhance their experience of caring, enabling them to care more effectively, and continue caring for as long as needed. A combined individual and holistic approach to address practical solutions, emotional/psychological strategies, and economic resources are the foundations on which the need for this research is based. By examining the individual’s approach to caring, the beliefs, ideals, and skills, with a holistic approach that involves all those experiences and relationships that affect the individual, a greater breadth of knowledge is gained about the lived experience of the informal carer.

Historically women have been perceived to be the carers of both children and those in ill health (Calasanti & Bowen, 2006) within the family. Ten years of research (Figueiredo *et al.*, 2016) continues to identify gender differences in the amount of time given to caring, tasks allocated, and the general prevalence of male carers within the home (Russell, 2016; Carmichael & G. Ercolani, 2014; Del Bono *et al.*, 2009). In practice over the generations, men have been excluded from the caring role within the home and family due to the historical work and role of women. This has led to a lack of practical skills in some men needed for this role, for example home management and nutrition and cooking, and a lack of exposure to the demands and emotional investment needed for caring for those that are ill (Calasanti, 2007).

Estimates suggest that those over 60 years will account for 22% of the population by 2030 (Gomes & Higginson, 2008), highlighting that by this time the numbers of people dying at home will double and those caring for them will be elderly themselves. If this continues, the need for community based palliative care services, both generalist and specialist, will increased, to support those caring for the dying at home (Hennings *et al.*, 2010; Lawrence *et al.*, 2011). As life expectancy rises in the years ahead for the general population, Xie *et al* (2008) suggest that the number of people with multiple physical and cognitive needs, due to increasing older age, will further increase the pressure on palliative care services. Collaborative working between specialist services and generalist services, is therefore needed to enhance the care the patient receives and those that care for them. Expert knowledge and educational needs of professionals are

crucial to facilitate care for those with advancing disease, as the demand for specialist palliative care services increases.

However, to understand the carers' experience, a research platform is needed to hear and record the carer experience in depth, and to find out how they make sense of their experience themselves. This chosen platform is phenomenology.

1.4 Phenomenology

Phenomenology is the 'study of human experiences and the way in which these experiences are perceived' (Langdridge, 2007). There are two main phenomenological approaches, descriptive and interpretive. Husserl (1859-1938), developed descriptive phenomenology, the belief that understanding of others experiences was a description of their experience by them. He believed that this could only be understood by another, or researcher, by 'bracketing', or denying the researchers previous knowledge. Heidegger (1888-1976) however, developed interpretive phenomenology, or hermeneutics, believing that expert or personal knowledge was impossible to ignore when conducting phenomenological research (Dowling, 2004). Heidegger believed that one's experiences are linked with and central to social, cultural, and political beliefs, influencing the decisions people make (Heidegger, 1926). These two approaches form the basis of the phenomenological movement. By using this Heideggerian or hermeneutic approach, in-depth exploration of the lived experience of the carer and what is important to them can be undertaken (Parsons, 2010). This phenomenological approach has been described as connecting meaning with perception (Polit & Tatano Beck, 2004; Cassell & Symon, 2004).

Phenomenology is rooted in examining language, both written and spoken, (Langdridge, 2007). This process leads to a shared understanding of the experience in this case, the carers' experience of caring for someone with advancing cancer and/or dementia (Smith, 2007). By using an interpretive phenomenological approach to understanding the carers' experience, this experience can be understood by others and their needs explored (Reid *et al.*, 2005). By using in-depth conversation, active listening, and interpretation of the carer experience, one can begin to understand their experience (Smith *et al.*, 2009). The idiosyncratic detail produced by the richness of the experience retold will increase our knowledge of what it is to be a carer.

Phenomenology was the chosen methodology for this research study as it enabled in-depth exploration of the carers' experience whilst acknowledging the context for this experience and the influences that may affect this experience (Shaw, 2011). The use of phenomenological studies within the field of health and social care has increased our knowledge of the lived experience for carers giving primacy and validity to their experience (Smith, 2007). The individuality of the carer's experience is central to the co- production of knowledge between the carer and the professional. Detailed exploration of the lived experience for the carer creates understanding (Abma, 2002). A phenomenological approach to this area of study adds depth and texture to the known descriptions of being a carer, and will help clarify the complexity of the experience being examined (Smith & Rhodes, 2015).

Having identified the area of enquiry i.e. the informal carers experience of caring for those with advancing cancer and/or advancing dementia, known research in this field was accessed to firmly establish any gaps in the understanding of this

experience. An appropriate research question was then formulated. The intention for this study was not to replicate work already undertaken, but to increase the knowledge and understanding of the lived experience for these carers.

2. Rationale for Study

The need for the study discussed in this thesis stemmed from the findings of a bereavement study I conducted with the carers of those with dementia. These carers' experiences were humbling and poignant as they recalled the care their loved ones received as the end of their lives approached. Amongst the many feelings expressed by the carers, experiences of loneliness, social isolation, and a lack of care for themselves during end of life care were important issues (Bainbridge *et al.*, 2009). These carers also identified a lack of support services from professionals for themselves as carers, and the levels of spiritual care, psychological and psychosocial care they received was variable and largely inadequate.

My professional role as a palliative care clinical nurse specialist focuses on end of life care for those with cancer albeit that this is only a part of a wider palliative care perspective. The palliative nature of both these diseases, advanced cancer and later stage dementia, highlight the complex needs of carers as they carer for those at the end of their lives. The particular needs of carers at this time suggests that supporting these carers remains poorly understood (Rokach *et al.*, 2007). This work by Rokach suggests that carers caring at the end of life face different challenges than those caring for children, young adults, and chronic diseases. These differences include meaningless in the task, their own mortality, and loss

of hope. Although my primary role is with patients, supporting the needs of the carers and families of those patients at this time was also part of my role. By supporting the carers in their caring role they would be able to continue caring and cope with the demands of that caring. Supporting the carers as their relationships changed with those they care for, and their family and friends was something that at times was difficult to do well. This duality of roles as a professional was because my main role was with patients and end of life care for them is complex and exacting. Caring for carers and families is also complex and exacting and deserves equal attention from professionals. It is acknowledged that other patient groups, not just those with cancer, and carers need care and support at end of life, as symptoms may become complex for the patient and the care of these symptoms complex for the carers (Addington-Hall *et al.*, 1998).

The issues of social isolation and loneliness, linked with poor health of our elderly population, increased rates of depression, and social exclusion by a lack of awareness of these issues, are within our power to address and rectify as a society. This experience, as demonstrated in the recalled experience of carers in a previous research study by the author, suggests that supporting informal carers may improve their experience of caring. The knowledge gained of the experience of social isolation and loneliness for this group will enhance the service they receive from professional service providers and lead to a more educated profession delivering this care.

The needs of informal carers caring for those with cancer and/or dementia at home as the prevalence of these diseases continue to rise, needs to be understood. Their experience of social isolation and loneliness, as highlighted by

recent research, is not well understood in so far as it does not address the importance attached to those issues as experienced by the carers. Whilst the experience of isolation and loneliness is undisputed for some carers, the complexity of that experience and a deeper understanding of it by others, is needed to enable support to be given and directed to carers from detailed examination of their individual experiences.

A wider network of informal carers, who have not had a voice, need to have their experiences understood. There is an increase in the numbers of men taking on the role of caring for family members whose experiences and needs are poorly understood (Calasanti, 2007). By giving a voice to their experiences, new avenues of support may be identified as well as highlighting difference and nuances hitherto not realised.

Given the above, it is timely and necessary to carry out an in-depth study of social isolation and loneliness as experienced by informal carers.

3. Systematic Review

A systematic review of published research was undertaken to highlight what is known about the subject area and what is missing from the knowledge. The results from the systematic review were then used to develop the research question. This approach was used to give an exhaustive background of knowledge to this study of informal carers, caring at home, for those with advanced cancer and/or dementia. The paucity of literature surrounding end of life issues for informal male carers became evident. Whilst systematic reviews have been traditionally used to synthesise data from quantitative studies to produce meta-analyses, this process of review is a thorough and transparent

process that clearly informs the development of a research question. Using a standardised Preferred Reporting Items for Systematic Reviews and Meta-analyses format (PRISMA), Liberati (2009), to identify the published research, all studies were scrutinised in the same way. By using this approach all types of research were accessed, providing a comprehensive basis from which to conduct this carer study. Medical subheadings (MeSH) were used to standardise the language used to access research. The search process as described below, outlines how the search process was completed. The search was independently verified by the University of Warwick Research Support Librarian, and research collaborator Dr. Ray Owen. Assessing the research papers accessed for inclusion in the study by independent collaborators ensured that the selection process was transparent and validated.

3.1 Definition of informal carer

For the purposes of this systematic review and my thesis the term informal carer encompasses any immediate family or lay carer, friend or relative caring for those who are dying. Professional carers i.e. doctors and nurses, or paid carer research studies were not included in the review.

3.2 Search strategy

The published literature was accessed by determining search terms and searching medical, nursing, and psychological databases. The terms used were: carer experience, dementia, cancer, isolation, terminal care, carer burden, loneliness, home-based care, family caregiving.

The databases searched were Medline, Cinahl, Embase, Psych Info, Ahmed, Cochrane Library, and Assia. These databases comprehensively cover the different care disciplines and publish peer reviewed research. MESH terms were combined to ensure all available research was found. Combining multiple search terms allows all the different categories to be included during the search process.

Table 3.2.1. MESH Headings For Search Terms

Carer	Caregiver	Carer Burden/stress	Informal Carer	Family Carer Home Based care
Cancer	Neoplasm Tumour	Malignant	Palliative Care Terminal Care	End of Life
Dementia	Alzheimer's	All Dementias		
Isolation	Social Isolation	Loneliness		

Research studies were included in the search process from 1990-2013. The time frame from 1990 ensured that relevant research was captured. A time frame of 23 years was agreed with my supervisors as sufficiently long to capture the early understanding of the informal carers experience where studied, and not too long a time period as to include outdated and irrelevant research. There were more papers published between 1990-2000 than after this date. The systematic review was completed in the year 2013.

Searching the literature was then widened to identify adjacent fields for example research that focused on single parent families, prisoner isolation, and 'traveller families' research to ensure that a wide range of experiences, methods, research design and differing points of view were included where appropriate. This

additional searching revealed no new articles for inclusion in the systematic review.

Grey literature, or unpublished research, was also considered. Managing Access to Grey Literature Collections (MAGIC), GrayLit Network, and 'Gray Literature Resources to Locating Unpublished Research' sites were searched resulting in no further literature for inclusion in the review.

The results from the search strategy identified a range of research across dementia, non-cancer diseases and cancer where the carers' experience and isolation was highlighted in the results section.

Following a process of identification and categorisation, as identified on the PRISMA flowchart (Figure 7.2.1) relevant research was accessed and scrutinised for inclusion in the review. The Critical Skills Appraisal Programme (CASP 2009) was used as the critical appraisal tool for the research found establishing the quality of that research and ensuring that empirical research was the norm as far as possible. Most of the published research in this field of carer experience was identified as quantitative in approach and also intervention- based. For the few studies that were qualitative the critical appraisal process was applied whilst acknowledging that the synthesis of qualitative data is a complex and much contested process. For these papers the carers experience was the main focus for the findings, and as such addressed the research area of interest. Synthesis of qualitative data however, thematic synthesis and narrative synthesis, continue to attempt to combine complex data from complex research questions, to highlight complex findings (Lucas *et al.*, 2007; Barnett-Page & Thomas, 2009).

Despite adopting specific search terms for the relevant databases, research papers that were not eligible for inclusion in the literature review did appear in the

search finding. These papers did not address the area of research and were excluded, they included scientific papers where the term isolation is used for genetic studies and cell biology. This process of exclusion occurred at the title stage and also when reading the abstracts, before the final number of papers were accessed for inclusion. Exclusion of papers also happened at the abstract stage as examination of the findings did not always represent the study aims and objectives.

Inclusion criteria:

- Family carer experience past or present.
- Family carer isolation/loneliness identified in the main results of the research.
- Home –based care.
- End of life care.

Exclusion criteria;

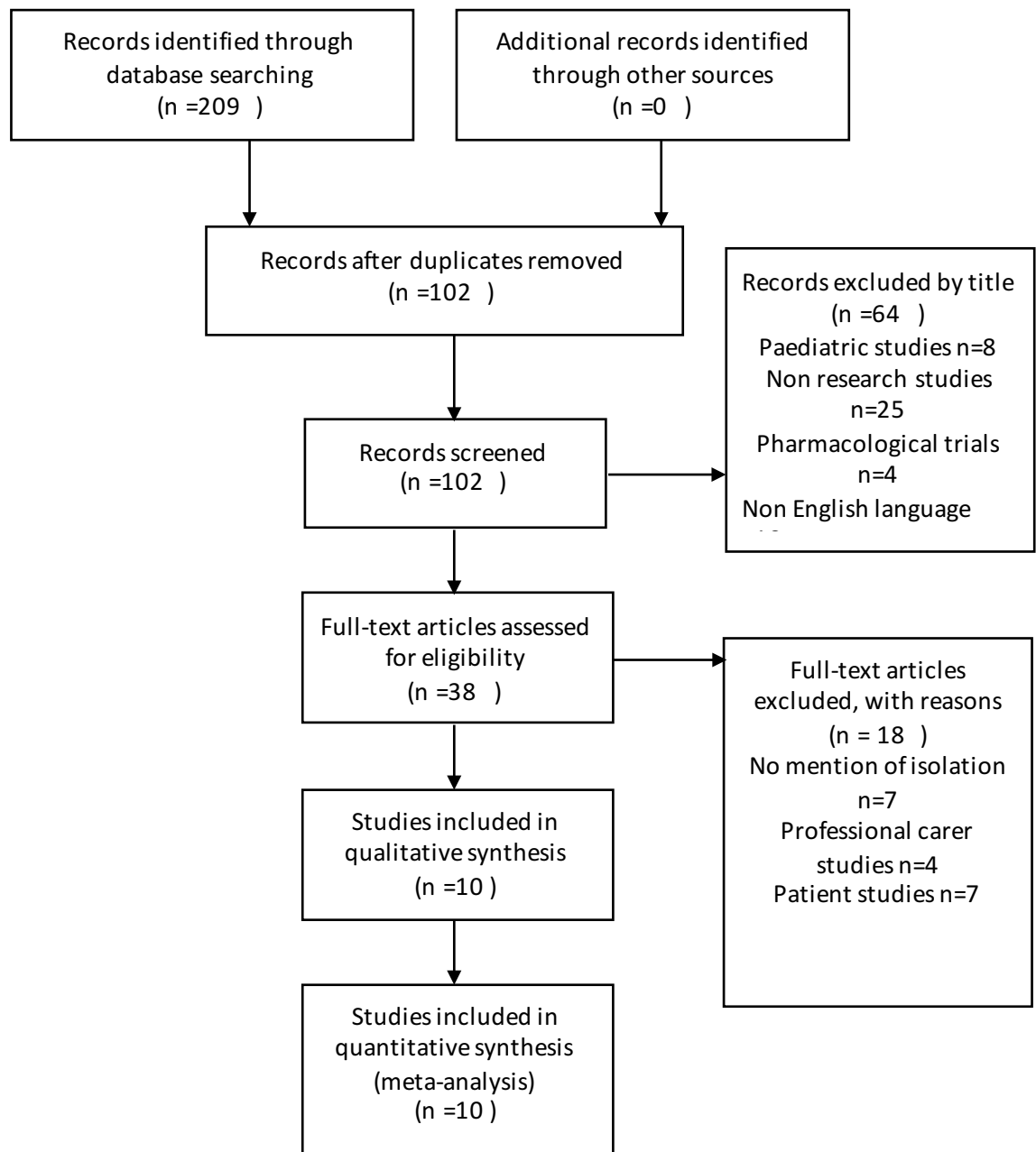
- Non-English language studies.
- Professional carer studies.
- Care settings other than home based.

A systematic approach for filtering all the papers for the review was undertaken maximising validity and appropriateness. A comparative study of appraisal methods for a systematic review concluded that a formal approach to appraisal of research papers, such as CASP, was more likely to produce agreement between reviewers than more intuitive approach (Dixon-Wood *et al.*, 2005). Spencer *et al* 2003 suggest that four principles should be considered when reviewing research evidence:

- contribute to the existing knowledge of a specific area/topic
- have a robust design pertinent to the question asked
- be robust in its execution and
- make credible claims from the data/results generated.

The process of review and the frameworks needed, to address complex research are by their very nature complex too. However, continued debate regarding the synthesis of qualitative research continues (Campbell *et al.*, 2011). The use of technology to organise, code and synthesise data is seen by many as an efficient way of managing large amounts of data from qualitative research, for example the use of coding themes digitally, (Crowston *et al.*, 2012) and merging of these findings across different approaches. Audit, expert opinion, and service review were not included in the systematic review, as empirical research that has undergone a process of ethical approval and peer review is deemed the highest quality research for consideration (Polit & Tatano Beck, 2004; Department of Health, 2005).

Figure 3.2.1 PRISMA Flowchart – Systematic Review



(Liberati *et al.*, 2009)

3.3 Results of Systematic Review

The results of the systematic review revealed 20 papers for inclusion (Appendix 1). The results of the systematic review revealed that there was an equal number of papers addressing those issues for carers of cancer, and for those carers of dementia. Several papers included more generic descriptions of caring with little or no details as to the disease or diagnosis of those being cared for. These 20 papers were categorised as:

- Studies of cancer carers' experience
- Studies of the dementia carers' experience
- Generic experience of family caring at home

The informal carers' experience of end of life care has been researched many times in the previous 10 years. The end of life care research included in the systematic review by Proot et al 2003, Cain et al 2004, and Shanley 2011 identified a carers experience that continues to be studied. The complexity of the carers' experience continues to warrant further exploration and understanding. The research conducted over the decade continued to highlight a varied and complex area of challenges for family carers at a time when reliance on them to provide care for their loved one was increasing.

The geographic profile of the studies included in the review suggest that the majority of studies were North American in origin (n=14), European studies were smaller in number (n=4), with those conducted in Australia (n=2) providing an insight into the widespread global research undertaken. These geographical results are not surprising when considering the populations of the different areas, and therefore the greater numbers of potential carers to be researched account

for the greater numbers of studies conducted in North America. However, they also highlight a gap in the current knowledge of specific experiences for those carers in the UK providing end of life care for those at home with cancer and/or dementia.

The four studies below are linked together as they document the carers experiences of social isolation as a direct response to their caring role.

The study by Boland and Sims (1996) was included in the systematic review as it was the earliest research identified in the search strategy and forms the basis for the interest in this area of carer research. Seventeen family carers were interviewed at home regarding their experience of caring. It documents a wide variety of ages cared for, from 14 months to 87 years. The results are poorly presented. The evidence presented in the findings from this study suggest that caregiving is a burdensome experience, framed by responsibility and isolation. The major finding of isolation, however limiting and stressful, was seen by others in the study as a protective and positive time of caring at end of life. The time-limiting factor involved in caring for someone at end of life suggests for some carers, a protected and intimate time with those family or friends, was seen as a positive time for them both. This study looked at the general stresses and issues of home-based caring for a wide group of carers and the findings reflect this in their broad themes (Boland & Sims, 1996a).

A hermeneutic approach to data interpretation was used by Albinsson and Strang (2003), that gave a sense of complexity and individuality to their study. Twenty family carers were interviewed ten of which were women, ten were men. Although this study was conducted in two care homes and one day-care facility, the example of a change in methodology, from quantitative to qualitative, warranted

its inclusion in this review. This qualitative study design using the hermeneutic approach developed by Heidegger (1889-1976) and Ricoeur (1913-2005) strengthens the move away from quantitative approaches to the experience of informal carers, and builds on the development of phenomenology and its strengths and indepth enquiry to the issue of carer research. For the carers' interviewed, issues around freedom, isolation, death and the futility of life were central to their experience. This change in methodology to a qualitative approach to address the carers experience allowed for complex themes to emerge that were part of the carers' experience. This study was an early example of a qualitative study in this field and the findings of isolation during the carers' lived experience highlighted restrictions in the carers' freedom due to their caring role, reflections on the impending death of those they were caring for, and the carer trying to make sense, or attach meaning, to their caring experience for themselves. This study suggests that central to the carers' experience is the issue of isolation (Albinsson & Strang, 2003) .

Thirteen carers of those with a terminal illness being cared for at home were the subject of a semi-structured interview study in the Netherlands (Proot *et al.*, 2003). Whilst the particular disease was not documented in the research, the criteria for inclusion in the study was a life expectancy of 3 months or less. The findings from the five carers' interviewed included those interviews that had taken place as a dyad, and the findings from the interviews were not attributed to either the patient or the carer in the paper presented. Earlier research findings of restricted carer activities, isolation, and reflection around death, were similar to Albinsson and Strang (2003). Researchers agreed that common features of the family carer experience encompass, feelings of burden, restricted freedoms,

feelings of a lack of competence, emotional strain, financial strain, as well as the struggle associated with accessing the practical support and services needed to care for those dying at home. The findings from this study seem to suggest that the struggles and strain of those caring for a loved one with a terminal illness at home continue until the very end of life. A lack of information, emotional, and practical support were highlighted in the end of life caring experience for those carers. It could be argued that a lack of provision in these areas is evidence of poor care that both the patient and carer experience.

Social isolation or community isolation was a feature of the carers' experience in a study for those with cancer and or Human Immunodeficiency Virus (HIV) and their carers conducted by Cain (2004). Focus groups followed by individual interviews were conducted with 42 carers. The findings from this study highlighted the overwhelming demands of providing care for those at home, the cost of this care for families and the difficulty in negotiating the healthcare system in Canada. For the carers in this study however, social isolation was experienced as a direct consequence of their caring role. The stigma attached to those with HIV or those caring for someone with HIV was evident in the findings. Grounded theory was used for data analysis with the generation of four main themes across all six groups. However, there was no documented discussion on the implications or importance of their findings in the published paper and how these differed or concurred with previous studies (Cain *et al.*, 2004).

These four studies above show that the informal carers' experience of caring at home is one of stress, carer vulnerability, overwhelming caring demands in terms of time, and social isolation as a direct result of the caring role.

The following three studies examine the relationship between the carers experience and those that they are caring for. A questionnaire study of 37 cancer patients, 78 carers, recruited from a hospice in Israel, and 128 members of the general population indicate that these groups of people cope with loneliness differently e.g. the dying patient scored lower on a social support network scale, activity sub-scale, and higher on a religion and faith support scale (Rokach *et al.*, 2007). A 34-point questionnaire was used to facilitate their views and experiences of loneliness, as well as individual interviews. Recording a 10% uptake in participation in this research study, the authors do not specify whether this was patients or carers or the general public. The different groups had their physical, social, emotional, and spiritual needs scored by a process of anonymous responses to the questionnaire. Whilst the focus of this study was the experience of loneliness, very little data was included for the carers specifically and so their experience was poorly defined. The general nature of the findings presented for the population as a whole in this study, identify the significantly lower scores on a religion and faith subscale measure for this group. The correlating high scores on the social support network and increased activity measures, point to assumptions already held re the nature of ill health and the needs of the dying. The findings of this study therefore adds little to the known carer experience generally; however, it could be argued that positive knowledge may have been gained for the specific group researched in Israel. In this case it is harder to extrapolate these results to the carers' experience in the UK on the information given in the study (Rokach *et al.*, 2007).

Sherman and Boss (2007) carried out a qualitative interview study of 9 women who had married for the second time late in life. Their study shows that 'relational

boundary ambiguity' (p263), makes caring for those spouses with dementia harder than for carers with no step family relationships (Sherman & Boss, 2007). A grounded theory approach was applied to the data in this case exclusively women's experiences. The main themes of increased carer isolation due to complex family dynamics; poor relationships with adult step- children due to the rejection of new marriage; conflict towards those they are caring for, and desertion by family members. These findings are pertinent, as it suggests that complex family relationships make the caring role more difficult. This is certainly an area for further exploration, to investigate how the caring role is adversely or positively influenced by family dynamics. Whilst the results of this study are very specific in terms of population characteristics, relational influences and interactions are common to all experiences.

Carter (2010) suggests that isolation and loneliness are also an issue for carers of those with advanced prostate cancer. In this study of 19 family carers': 15 wives; 3 daughters; and 1 son, feelings of uncertainty of the future and a need for information increased the isolation felt by these carers. However, those caring for someone undergoing chemotherapy for advanced disease, experienced an additional carer burden and isolation due to a lack of practical support as part of the caring experience. This was cited as a major concern and difficulty during additional focus groups that were held to corroborate the findings of the semi-structured interviews (Carter *et al.*, 2010).

These three studies above demonstrate the complexity of the carers' experience in terms of relationships and how these are changed by caring.

The following three studies, the most recent found in the systematic review, highlight further examples of social isolation and loneliness. Practical ways of

addressing these issues have been researched with peer support and the development of information and communication technology (ICT) technologies and applications.

Duggelby (2011a) qualitative bereavement study of 10 carers is included in this review because of the result citing community connectedness and isolation was cited as a major finding. Whilst 12 professionals' opinions were presented in a focus group, the main finding reported from the study was the issue of carer community connectedness and social isolation. The use of telephone interviews, as seen in other studies may be questioned; nevertheless the telephone is an increasingly used format for research over recent years when possible geography and access to research centres is difficult for potential target populations i.e. the elderly or those separated by travelling distance (Duggelby *et al.*, 2011). This paper begins to identify the power of community connections with others whilst caring at home.

Shanley (2011), qualitative interview study of 15 dementia caregivers; 8 females and 7 males, suggests that one of five themes common to all interviews, was one of managing loneliness as a carer. The other themes highlighted were getting practical support, trusting others with care, anticipating and experiencing death. This study highlighted the important role that family, friends and professionals play in the carers' need for genuine understanding and connection. It is suggested that many friends and family withdraw from both the person with dementia and the carer at a time when support is needed. An aspect of the loneliness experienced by the family carer was the loss of connection and intimacy with the person with dementia. This study was a more personal account of the experience of a carer than had previously been addressed. The ways in

which these carers managed their loneliness supports the need for support groups, individual peer support and maintaining existing friendships (Shanley *et al.*, 2011).

A study of 14 carers of those with dementia conducted by McHugh (2012), whilst highlighting already known elements to the family carer experience, considered specifically targeted information and communication technology (ICT) to be developed to support carers to minimise their sense of isolation and loneliness. Of the carers interviewed 8 were male and 6 were female. Grounded theory was applied to the data and subsequent themes were identified. The main themes were carer support needs, social isolation and the patient-carer relationship. Whilst existing ICT can connect the carer with friends and family through the use of social networks for example, the use of ICT for enhancing relationships between the carer and the cared for involve the development of supported communication systems, reminiscence, and entertaining displays or videos that allow access of public spaces from the home. Information and the education about dementia through ICT developments may enhance and enrich the carers' experience (McHugh *et al.*, 2012).

These studies above conclude the qualitative research found during the systematic review for the issue of the carers' experience of social isolation and loneliness. Examining the issue of social isolation and loneliness from a qualitative research perspective has highlighted that social isolation is easier to identify with by carers themselves than loneliness. The terms are used simultaneously and are interchangeable in the literature cited and describe a wide range of experiences.

The following papers accessed for the systematic review were quantitative in approach. The following two American studies looked at the link between carer isolation and poor health.

Beeson et al (2000), secondary analysis of 242 dementia carers, found that isolation and loneliness were significantly linked to depression rates in carers. Their study population consisted of 35% husband carers, 52% wife carers and 32% adult children carers. The mean age of these carers was 72 years for the spousal carers and 52 years for the adult children carers. The authors used hypothesis testing to generate the data, with self-reporting depression and loneliness scales to generate stress scores. Relational deprivation scores were also used to generate an outcome score. Taking into account background and context, primary secondary and intrapsychic stressors, mediators and outcomes were identified. It was extrapolated from these data that increased carer isolation and loneliness led to poor relationships with family, friends, and those they were caring for, further compounding the isolation and feelings of loneliness as these relationships deteriorated. The study also highlighted that loneliness scores were the only variable that could reliably predict the likelihood of depression in carers. From this study we can begin to see that the issue of loneliness and isolation has a major impact on the experience of home caring for informal carers (Beeson *et al.*, 2000).

A longitudinal study over 4 years by Robinson-Whelan (2001) demonstrated that depression and loneliness are a feature of the carer experience for those with dementia. This large questionnaire study canvassed 49 former carers, 42 continuing careers, and 52 non-caregiving adults, 64% of all respondents were women. The findings showed that feelings of depression and loneliness continue

even when the caring role ends; the feelings of depression and loneliness continue for three years post caring. The effects of long term caring they suggest, are poorly understood. This research is pertinent to the long-term caring associated with dementia and the trajectory of that disease. However, the nature of depression and loneliness may be different for those caring for someone with cancer for example, where the longevity of the caring role may be much less (Robinson-Whelen *et al.*, 2001).

The following two studies, one in USA (Matthews 2004) and the other in Sweden (Andren & Elmstahl 2008), looked at the two different diseases of cancer and dementia separately. They did however, report similar results.

A quantitative questionnaire study of 152 family carers of cancer survivors looked at quality of life indicators for carers (Matthews *et al.*, 2004). Questionnaires were used to elicit their results. Twenty sections in the questionnaire covered many aspects of the caring role, expectations of that role, behaviour, emotional strain and quality of life descriptors. This comprehensive understanding of the role is represented by the researchers, but areas potentially missing from their findings are the relationships both social and personal that the carers experience. Inclusion of questions on relationships may have highlighted a different or a more complete picture. They did however, identify the need for ongoing research into this area (Matthews *et al.*, 2004).

The results from the Swedish study (Andren & Elmstahl, 2008) duplicate earlier research findings by Mathews et al (2004) in this area. Questionnaires were given to 130 female carers of those with dementia. This study showed strong links between carer burden, isolation, disappointment, a sense of coherence, (used

here to denote competence in the tasks needed for caring), and carer health scores. This study shows the continued use of questionnaires for carer experience research and as such repeats known issues, themes or difficulties.

A complex study conducted in the Netherlands consisted of the examination of multiple support approaches for carers attending the Meeting Centre Support Programme (Droes *et al.*, 2006). This large study of dementia carers, 71 across 3 different centres, incorporated 6 different self-reporting health scales including a loneliness scale, a competence scale, a coping scale, a social support list, and a neuropsychiatric inventory. These were used to evaluate the support needed for carers. A major finding from this study was the positive impact the support programme had on delaying admissions of those with dementia to a care home; that attending a support programme for carers would potentially reduce the need for crisis admissions to care homes for those with dementia. This may in turn facilitate patient and carer preferred place of care choices to be accessed in the absence of a crisis.

A telephone intervention support study (Stewart *et al.*, 2006) for carers of those with dementia or a stroke instigated a peer support programme with weekly telephone contact of an hour to discuss carer concerns. It was not documented whether the carers in this study were male or female. The telephone sessions were recorded and transcribed and field notes were also taken into account. Inductive analysis was applied to the framework for coding responses from the transcribed conversations, developed by the investigators, supported this use of regular telephone contact. The ongoing support lasted for 6 months and the findings showed a decreased need for support from professional services, increased feelings of competence and confidence, reduced feelings of loneliness

and reduced feelings of burden during this time. It could be argued that the peer support element to this study may have been instrumental in the positive findings of the intervention. Thus the value of the exploration of the carers' experience by those who already have some understanding of the role itself, can bring credibility and empathy to the process of support. Both these intervention- based studies show the importance of peer support for carers and the benefits of supporting them in this way.

Family caregivers that experienced increasing carer burden and isolation during their caring role cited this as a factor in the decision to place those they cared for at home in a professional care setting. This paper by Bramble et al (2009), was included in the systematic review as the majority of care for those with dementia had taken place in the home prior to the move to a formal care setting. This qualitative study, using semi-structured interviews and thematic analysis, captured the experiences of seven women as the dominant sample out of ten participants. Feelings of loss and guilt alongside family carers wishing to connect with care home staff, and the need to continue with the personal care of their relative, all added to the carers' sense of loneliness when those cared for at home were then admitted to a formal care setting. It can be seen that the feelings of loneliness and isolation continue when the caring role ends suggesting that this is a powerful element to the carer experience, not easily rectified by addressing practical issues alone. These findings also suggest that the experience of social isolation and loneliness impact on the carer into later life and may affect and influence their own ageing adversely (Bramble *et al.*, 2009).

Sanders (2009), offers an insight into the issues that spouses, adult children and female carers experience when caring for those with dementia. Social isolation

and loneliness were experienced by 44 family carers suggesting that these health risks play a pivotal part of the caring role. The carer initially completed questionnaires and were then interviewed. The interviews were differentiated by location, with spousal carers being interviewed at home, whilst adult children carers were interviewed on the telephone. There was no documented reasoning for this and as such, leaves an unanswered query as to this different interviewing approach. Carer isolation from family and friends and also from those with dementia were identified as a different entity. A greater understanding of the experience of isolation from family and friends for the carer is vital if the carers' experience is to be understood. The themes emerging from this study - yearning for the past, regret, grief, and restricted freedoms - paints a picture of higher carer grief levels than seen in previous studies (Sanders *et al.*, 2009).

A questionnaire study, in Connecticut USA, considered the effect caring has on depressive symptoms, health, work and social isolation in the general population of Farmington, where the academic institute was situated that conducted the research (Robison *et al.*, 2009). In this quantitative randomised postal study, 2,761 caregivers' responses were accepted, for the groups 42-60yrs, and the over 61yrs. A comparative sample of non-carers, 1150, were also canvassed making a total of 4041 adult responses. Two hypotheses were tested;

- Caregivers report worse health and psychosocial outcomes than non-caregivers.
- Caregivers facing more stressful caregiving situations will exhibit poorer health and psychosocial outcomes.

These hypotheses were tested with a statistical analysis of a depression screening and logistic regression test of 6 health and social outcome measures.

Their findings indicated that caring per se does not negatively impact on depression, health, work, and social isolation if one is healthy. If one is already aged or in poor health, then caring is more difficult. The results from this study are difficult to extrapolate to a specific carer group as the randomisation of the sampling population during recruitment to the study, gives an extensive population with diverse experiences. For the purposes of this systematic review this population is too diverse to generate any clear evidence for the experience of the carers central to this proposed research. However, one can assume from an ageing population and the area of end of life care considered, that those cared for at home with cancer and dementia falling largely into the older age groups in society, are in turn, cared for by those with their own health needs and of a comparable age (Gomes & Higginson, 2008).

Additional work by Leggett et al (2011) suggests that carers caring for those with Lewy Body dementia have additional stresses as the condition is poorly understood by professionals, family, and friends alike due to its relative rarity. An internet study was conducted with 611 family carers of those with Lewy Body dementia in the United States of America (USA). The questionnaires used focused on behavioural and emotional scale reporting, mobility scales, access to services questions, isolation issues, and the evaluation of any help they received. This study reported that the carer burden had 3 dimensions, role strain, personal strain, and performance worry. This less common form of dementia has symptoms and challenges that are peculiar to it, such as hallucinations and paranoia, and thus increases the carers sense of burden, isolation and general strain associated with caring for someone with a rarer form of dementia (Leggett *et al.*, 2011).

An overarching understanding of these results from the systematic review demonstrates the huge negative impact loneliness and isolation have on carer health. This influences their access to services for themselves and for those they care for. In a population already isolated and lonely (Windle *et al.*, 2011) and (Age UK, 2009), the caring role can continue to adversely affect their experience in society.

The research considered in the systematic review falls into four broad areas following examination of the results and thematic analysis of the data. Narrative data from the studies allowed themes to emerge across several studies linking to broad areas of experiences. The issue of family carer isolation was present in all the studies as befitted the inclusion criteria, however, this was explored to varying degrees as discussed above.

The four areas are:

- Linking carer isolation with poor health (Robison *et al.*, 2009; Beeson *et al.*, 2000; Bramble *et al.*, 2009; Robinson-Whelen *et al.*, 2001).
- Assessment of intervention (Stewart *et al.*, 2006; McHugh *et al.*, 2012; Drees *et al.*, 2006).
- Carer relationships (Sherman & Boss, 2007; Sanders *et al.*, 2009; Shanley *et al.*, 2011; Rokach *et al.*, 2007; Carter *et al.*, 2010).
- General caring issues (Duggelby *et al.*, 2011; Boland & Sims, 1996b; Robinson-Whelen *et al.*, 2001; Cain *et al.*, 2004; Matthews *et al.*, 2004; Andren & Elmstahl, 2008; Albinsson & Strang, 2003; Proot *et al.*, 2003; Leggett *et al.*, 2011).

As the evidence above shows, informal carers have been the subject of many studies over the years. Identification of geographical boundaries of the studies presented as a whole suggests that the majority of the research is North American, where the provision of health care is very different to that of the UK; an exploration of the carers' experience of isolation and loneliness in the UK is needed.

Further examination of those professionals researching this area revealed that the majority group (n=42), were academics working in tandem with clinical professionals, the largest group of those professionals (n= 26), being nurses. This may explain why the methodologies for the studies accessed are uniform in approach because the same groups of professionals are researching similar areas e.g. carer experiences. Doctors and psychiatrists (n=11), and psychologists/sociologists (n=7) make up the other disciplines represented. It may be that nurses find the needs of carers difficult to address when their primary caring role is with the patient but are no less aware of the needs of this group of people. However, the holistic approach to patient care involves the family and this may go some way to explain the similar research studies over a number of years at a time when financial and staffing levels are increasing the pressures on informal or family carers identified by the professionals involved in patient care. This however, should not preclude nurses from engaging in research but they should continue to strive to develop evidence-based knowledge from which to direct care and services.

Following a further detailed examination of the gender of research participants across the various studies included in the systematic review it emerged that, 61% of carers were women (n=3,149) making their experience the most widely

analysed. Most of the carers were spouses (n=770), out of total sample (n=1186). These findings are consistent with the demographics of the individual studies represented.

The conclusions from the systematic review identify that carer isolation and loneliness are features of the informal carers experience. The complex nature of those issues however, is not well understood, and as such a deeper investigation, exploration and clarity of knowledge is needed. Two studies addressed the needs of those caring for the dying at home, Cain (2004) and Shanley (2011) cancer and dementia carers' respectively. This paucity of research was identified worldwide. To have the most effective conversations needed to address the issue of carer loneliness and/or social isolation, conversations should be conducted in an inclusive and empathic environment. I propose that a qualitative research study is needed in the UK to understand the importance and value attached to the experience of social isolation and loneliness as experienced by informal carers. In-depth analysis of the findings from a qualitative study will add to the knowledge of this complex experience and will highlight potential means of support for carers.

The experience of informal male carers is poorly understood and I propose that a study of their experience is long overdue. To address their issues in an enquiring and non-judgmental way through qualitative research is needed to hear their voice and experiences. To highlight the issue of social isolation and loneliness the research question for this study needed to be non-judgmental and allow the lived experience of being a carer to be heard in its complexity.

3.4 Research Question

How does caring for someone with advanced cancer or later stage dementia affect informal carer's personal and social relationships?

4. Methodology

A qualitative research study was designed to address the research area of social isolation and loneliness in the context of men caring for someone with cancer and /or dementia at home. The philosophical approach to this study was an interpretivist one because interpretivism draws meaning from an experience allowing the nuances of that experience to emerge. Interpretation of the carers experience of social isolation and loneliness through language, beliefs, and interactions with others is the way in which new knowledge and understanding is generated. This is in contrast to, for example, a more Positivist approach, where quantitative data may be used to test a proposed hypothesis regarding the area of interest. By using a qualitative hermeneutic approach, the interpretation of human experience, a more nuanced level of enquiry can emerge from the findings. By combining the use of a sociological approach, how the individual exists within society, with a psychological approach, that considers the individual, the complex nature of human experience can be explored. By using this combined interpretation of the carers' experience elicited from the data, varying viewpoints with the same philosophical stance, can help develop new ways of understanding and new means of support may emerge.

Phenomenology, as an inductive, interpretive research approach, was chosen for this study because of its philosophical underpinnings of the lived experience of the individual. The attention given to the individual throughout the sampling process, data collection method, and method of analysis of data, confirms its appropriateness for this study (Starks & Trinidad, 2007). A comparison with discourse analysis, grounded theory and phenomenology was conducted before

deciding the theoretical underpinning of this study. The focus on language and interaction to create identity as seen in discourse analysis did not offer the same level of meaning attributed to those interactions that is the strength of phenomenology. This critique of these approaches the foremost distinction between DA and IPA (Biggerstaff & Thompson, 2008). Similarly, the themes generated by grounded theory, are not afforded the interpretation that is central to and the strength of phenomenology.

Phenomenology is a philosophical study of human experiences and the way in which these experiences are perceived (Smith *et al.*, 2009). This philosophical tradition was begun by Edmund Husserl (1859-1938) and developed by Martin Heidegger (1889-1976). There are 2 schools of phenomenology,

- descriptive phenomenology devised by Husserl, and
- hermeneutics/interpretative phenomenology devised by Heidegger,

Husserl's development of a philosophical enquiry into the origins of consciousness at the beginning of the twentieth century, saw the development of descriptive phenomenology (Langdridge, 2007). The philosophical theories that are embedded in this approach are;

- Intentionality – this is the awareness of something, and object or an idea. The relationship between the noema (what is experienced) and the noesis (the way it is experienced) (Langdridge, 2007).
- Epoche – 'leaving aside our assumptions' Also known as 'bracketing'.
- Reduction – distilling the textural description of the experience in detail using reflection.

- Imaginative variation – this is the process by which an experience is looked at from another point of experience.

Heidegger then developed phenomenology further to expand the understanding, significance, and interpretation of the written text. One of the ways in which his theory differed from Husserl's was that he did not believe one could bracket one's own experiences when trying to understand someone else's experience and how they make sense of it. He maintained that to establish or to make sense of an experience, that experience must be examined in the context in which it happened. This move towards an understanding of the experience 'being in the world' and 'of the world' highlights the idiopathic nature of this theoretical approach to the lived experience (Parsons, 2010). Heidegger's phenomenology developed the interpretive direction with the identification of;

- Temporality – the experience of time "what it is to exist" (Heidegger, 1926).
- Mood – the experience of the world through our moods e.g. anguish fear, the fear of non-existence.
- Being towards death – an awareness of needing to make our lives meaningful.
- Authenticity – the awareness of the individual in relation to the masses.
- Being with – this is the social nature of one's existence.
- Discourse – the importance of language.

As shown by Heidegger's stance an interpretive approach to life experiences encompasses the nuances of the individual experience, in context within the world in which they take place. This focus on making sense of the lived

experience is ideally suited to exploring the experience of being an informal male carer for the purposes of this study.

By choosing interpretive hermeneutic phenomenology to understand this lived experience, the individual is given centre stage, and as such knowledge and understanding are co-created.

The two positions of hermeneutic, interpretive phenomenology are;

prejudgement - pre conceptions and prejudices are part of the experience, and

universality - the person who expresses experiences and the person who understands them are connected by common human consciousness which makes understanding possible.

Hermeneutics is the uncovering of phenomena experienced by individuals through analysis of their descriptions. This branch of phenomenology focuses on a person's lived experience obtaining commonalities and shared meanings (Smith & Osborn, 2007).

Heidegger believed that human beings always relate to each other and objects in the world. He also believed that meaning is derived and determined in the context of these relationships. Heidegger used the term 'dasein' to explain "being in the world" (Heidegger, 1926) This enables a unique experience for each of us to be socially and historically contingent. This complex fabric of relationships, practices, and language (Parsons, 2010) describes how we live through those experiences.

Temporality is the concept of being in the world, simultaneously in the present, influenced by the past and looking to the future. This is a key feature and

philosophical underpinning of phenomenology (Langdridge, 2007). This sense of temporality gives context and circumstance to the decisions and the experiences we make sense of (Larkin *et al.*, 2011).

The Heideggerian philosophers that followed Heidegger, namely Gadamer and Ricoeur, refined their philosophical approach by examining the role of language in human experience. Gadamer believed that speech and in particular conversation, was the essence of understanding another's experience. Ricoeur's work looked at the use of metaphor in ascribing meaning to an experience (Langdridge, 2007). Both these elements of the ongoing development of phenomenology informed the study design of this research.

The methodology for this study is rooted in the Heideggerian form of phenomenology and as such applies interpretative phenomenological analysis (IPA) to the data analysis. IPA is a series of technologies that allow us to elicit experiences from others, and cluster themes that emerge from these experiences to help understand and make sense of them, as are the individuals who are experiencing them.

Data collection for phenomenological studies are mainly semi-structured interviews or focus groups (Eatough & Smith, 2010; Ritchie & Lewis, 2003). My experience of conducting clinical interviews and history taking with patients and families over many years led to a preference for semi-structured interviews for this study. Although research interviews and clinical interviews are not the same in both aim or structure, my expertise and confidence with clinical interviews made interviews the chosen method for data collection (Kvale & Brinkman, 2009).

Phenomenological in-depth interviews with research participants are led by the research question but not constrained by it. This allows the researcher to focus the interview without rigidly sticking to a pre-agreed format. This in turn allows the experience of the participant, whatever that may be, to be given the primacy and uniqueness of their own experience. This ensures that any preconceived ideas, assumptions and held beliefs by the researcher do not influence the retelling of the participant experience (Shaw, 2010). Research conducted from an interpretivist stand point, examines the relationship between our experiences and the world in which we experience them in. The lived experience of those being interviewed is reflected on by the researcher, with the research participant, during the interview to ensure accurate recording of the experience is being portrayed. In addition reflexivity, a deeper reflection of one's own thoughts to the lived experience being recalled, allows the co-construction of meaning and importance of the experience to the carer in this instance, in a holistic and socially orientated interpretation of the data (Shaw, 2010).

Using in-depth interviews for research gives an individual, unique and personal account of an experience to be heard. Hearing that personal view is always to put the person central to their experience, 'person-in-context' (Larkin *et al.*, 2011). The skills needed for these in-depth interviews are ones of empathic listening, allowing the silences to be heard, facial and body language to be recorded, encouraging active listening, warmth, and a non-judgmental attitude towards the participant (Eatough & Smith, 2010).

The process of examining the recordings from the participant interviews is rooted in their experience. It begins with the interviews being transcribed verbatim. Additional notes identifying the pauses, the body language and facial expressions, from the study field notes, and the feelings surrounding the interview as a whole, are added to the transcripts. These transcripts were then read through several times. The initial reading of the text familiarises the researcher with the data, and immerses them in that data. A further reading applies a descriptive process to the text, noting for example, what is being talked about broadly, the context of the interview, any repeated words, ideas, feelings and emotions. This re-reading and reflection on the text begins to identify the uniqueness of the experience being recalled, and begins the analysis of the data (Smith *et al.*, 2009).

The next reading of the text focuses on the themes that are emerging from the text. Line by line coding allows exact placement of these themes in the context of the interview, and also ensures that the evidence of a theme can be replicated during the process of rigour and reflexivity during the research process. Having identified emerging themes from the interview these themes are then clustered to produce subordinate themes, through a process of interpretation. This clustering of themes, producing the subordinate themes, has moved the interpretation of the transcripts onto a conceptual level of analysis, looking deeper at the meaning and making sense that the participant has made of their experience.

This process of interpretation and analysis of the data at this stage, uses an approach called the Hermeneutic Circle (Smith *et al.*, 2009). This process developed by Smith *et al* (2009) allows for a deeper understanding by the

researcher of the experience of the participant. Here the understanding of the 'part' can only be understood in the context of the 'whole'. For example, the use of a 'word' can only be understood in the context of the 'sentence' in which it is used. 'I am lonely' can only be understood by the meaning and value that the participant places on that statement. By itself a word or phrase means very little until it is placed in context by those who verbalise it (Smith *et al.*, 2009). By using this circular approach to the analysis of the data, the researcher can examine and re-examine the meaning of the data presented by the participant. In everyday life making sense of one's experiences may take this form. For example, having an experience, linking it to past experiences, reflecting on one's own beliefs and understanding of that experience, and then making sense of that experience for the future is a way of making meaning of our experiences. When a researcher is then striving to understand an experience retold to them during a research study, he or she applies their analysis to the experiences recalled by the participant. This is described as a double hermeneutic circle. These levels of analysis are central to phenomenology and by using IPA highlights the strength of this approach when researching lived experiences of others.

Having used these processes to elicit the themes, and subordinate themes, the final level of interpretation and analysis across all the interviews, highlights the superordinate themes. The essence of the lived experience for the participants comes from the similarities and the differences seen across all the carers interviews. Reflecting on the idiographic process, looking for patterns, omissions, and disconfirming themes builds a rich picture, deeper understanding, and increased knowledge of the lived experience that comes from and is central to the data, (Smith, 2007; Smith, 2011). This advanced level of analysis goes

beyond the generation of themes only, to increase our knowledge and understanding.

Having considered the evidence presented in the systematic literature review, it was considered by myself that another way of accessing the carer experience may be by using an audio diary. None of the studies accessed during the systematic review had used non-traditional methods for data collection and as such it was thought that a different approach may lead to a departure from the semi-structured interviews of the past. This innovative way of capturing data has not been used for male carers, and may provide additional insights not captured by face to face interviews.

5. Pilot study

A pilot study was devised to critically evaluate the utility of audio diaries as a research method of recording informal male carer experiences. The pilot study would help to determine whether the use of audio diaries was an effective way of capturing the carer experiences when caring for the dying at home. If successful, it would enable an innovative method of data collection to be analysed and evaluated prior to the design of the main study. If audio diary recordings were adopted in the main study, the approach would represent a new and exciting format for the informal male carers' experience to be heard. The results of the pilot study directly informed the design of the main study. This pilot study, exploring the use of audio diaries, sought to add to knowledge of the range of possible methods available for carer research, and potentially identify an innovative way of capturing the carers' experience of caring at home.

5.1 Pilot Study Question

How effective are audio diaries for exploring informal male carer experiences of caring for those dying at home?

5.2 Methods

5.2.1 Inclusion Criteria

- Male carers aged 18yrs and older.
- Male carers of those dying with cancer and/or dementia at home.

5.2.2 Exclusion Criteria

- Male carers under the age of 18yrs.
- Male carers whose cannot speak English.
- Female carers.

5.2.3 Sampling strategy

To address the pilot study question, a sample size of 6 carers was needed to allow for a variety of opinions to be elicited on the effectiveness and usefulness of this method of data collection. Three carers caring for those with cancer at home and three carers caring for those with dementia at home were the numbers sought for the pilot study. Maximum variation sampling was the preferred sampling strategy as it allowed for participants with the exact experience of informal caring for someone at home with cancer and/or dementia to be recruited for the study (Langdridge, 2007). This sampling strategy, whilst allowing for diverse participants, also ensured that they had the relevant experience to answer the pilot study question.

5.2.4 Data collection

Audio diary recordings were undertaken to provide an in-depth exploration of the carers' experience of caring for someone at home with cancer and/or dementia. When they had agreed to take part in the pilot study contact was made with the participants by the researcher via a telephone call, and an initial meeting at a place of their choosing was arranged. This initial meeting enabled a rapport between the researcher and carer to develop as the study was explained. This meeting also allowed the audio equipment to be demonstrated for the recordings, and any questions to be answered. The carers were asked to record their experiences of caring at home for someone twice a week for four weeks. This time frame was considered to be the least burdensome for the carer. In addition, a simple record of the contacts, both social and professional, experienced by the carer for a two-week period, was requested to enable for a greater understanding of the relationship between isolation and loneliness. As already highlighted in the research accessed that provides the background for this study, the absence or minimal contact with others denoting social isolation does not produce loneliness per se. This relationship will be highlighted during this specific part of the data collection of the pilot study. These visits/ contacts were recorded in a small notebook given to the carer. It was intended that the content of the audio diaries would focus on the informal carer relationships with family and friends. An information sheet was given to the carers for reference at the initial interview, providing a written reference to aid diary entries. Technical information was also given in writing for the use of the audio recorder. Following completion of the four weeks, a closing interview would be conducted, as before, to discuss the

effectiveness of this tool. These recordings were taped and transcribed for the purposes of the pilot study analysis.

5.2.5 Ethical Considerations

The pilot study complied with and was reviewed by the NHS REC and the local NHS Trust R&D office. A proportionate review was carried out to determine the validity and robustness of the pilot study proposed Ref 13/WA/0412 (See Appendix 2). Whilst the principal investigator was not required to attend this sub-committee all the documents pertaining to the pilot study were submitted for examination in accordance with the ethical guidelines for research proposals.

Confidentiality was maintained throughout the study, at all stages. Throughout the data collection stage, the specific quotes and comments were not identified to individual participants. Through the careful use of general descriptors, such as place names, hospitals attended or professionals seen for example, no local knowledge could be used to identify participants or groups.

The anonymity of the participants whilst in the study was from everyone other than the researcher. Selection of the carers for the study was undertaken by a third party, (GP), and the names not revealed to the researcher until they had agreed to take part. Transcribed interviews were kept separately from the demographic data of participants to maintain anonymity whilst in the pilot study.

5.2.5.1 *Informed consent*

Consent to participate in the study was obtained by a third party in accordance with local ethics guidelines. This third party was a GP in the geographical area where the pilot study was taking place. Information sheets, consent forms and reply slips were developed to ensure the potential participants had the information

they needed to give their consent to participate in the pilot study (Appendices 2, 3, 4).

5.2.5.2 *Confidentiality*

The confidentiality of the carers taking part in the study was maintained throughout. The use of general descriptors and anonymous quotes also ensured that the participants could not be identified by a third party.

5.2.5.3 *Data Storage*

Diary recordings were recorded on a digital recorder by the carer. Transcripts of the closing interview between the carer and the researcher were anonymous. Transcripts and audio-recordings were kept securely in a locked cabinet. Personal data of the participants, kept for legal reasons, were kept securely and separately from the research data in a locked cupboard in an unremarkable or labelled folder.

5.2.4 *Data Analysis*

Analysis of the audio recordings for capturing the carers experience was twofold. Initially the recordings were examined for richness of data generated by this method of data collection. This included evidence of a variety of themes and categories emerging from the carers' experience, the ease of which thoughts and feelings of their experience are relayed through this method, evidence of non-compliance with the method, and evidence of any irrelevant data for example data or conversation that was not concerned with the caring experience i.e. political or personal comment/opinion. Analysis of the data generated would highlight the potential for using this method of data collection. A

phenomenological approach to data analysis was conducted in keeping with the philosophical and theoretical underpinnings of this thesis.

Additional analysis of the effectiveness of the audio diary as a process was also conducted at the closing interview. This focused on the use of the digital recorder, the burden versus benefit of this approach, and any other practical difficulties or discomfort with this method of recording the informal male carer experience.

5.3 Findings of pilot study

The findings from the pilot study are presented below. They give information as to who participated in the pilot study, the usefulness of the audio diary as a tool for recording experiences of informal caring, and the ease by which this form of data collection was adopted by the carers.

Table 5.3.1. Carer Characteristics In Pilot Study

Recruitment Centre	Potential Participants	Actual Participants	Carer Identification
Surgery 1	3 dementia carers	1 dementia carer	Carer A caring for wife
Local Alzheimer's Society		1 dementia carer	Carer B caring for wife
Surgery 2	4 dementia carers	1 dementia carer (then withdrew)	Carer C caring for wife
Surgery 3	1 cancer carer	None	
Surgery 4	2 dementia carers	None – Carer too ill, wife to ill	

The three carers that agreed to take part in the pilot study were recruited via two G.P. surgeries, and one Alzheimer's Society group. After the initial meeting to explain the purpose of the pilot study, answer any questions that the carers had,

and to demonstrate the digital recorder all the carers went ahead with the pilot study. After a week into the four-week period Carer C got in touch with me and withdrew from the study. His reasons for withdrawing from the study will be discussed later in this section.

Recruitment for the pilot study via the third parties identified was difficult and time consuming. As Table 5.3.1 shows, ten carers were approached and three agreed to take part. There was little information as to the reasons why those who declined to participate did so. Although the sample size was small it was agreed that the pilot study should continue to establish the informal carers' thoughts on audio recordings as a form of recording carers' lived experiences.

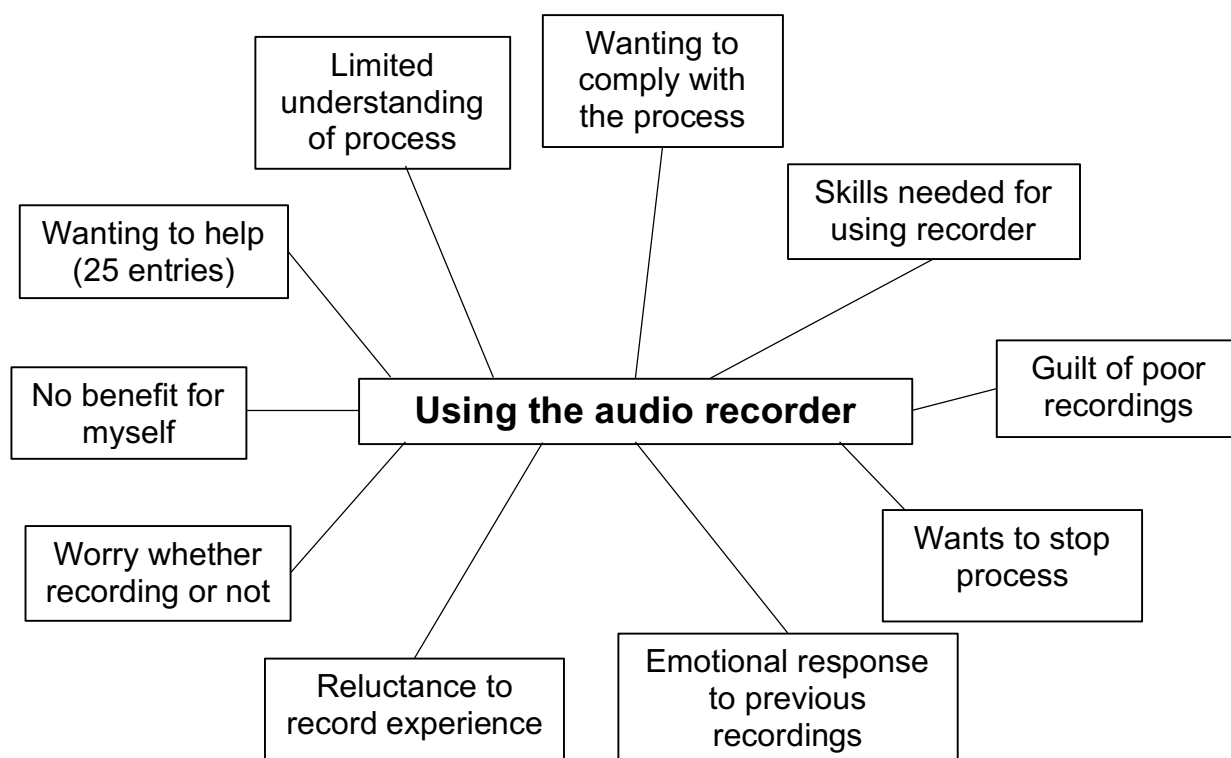
5.3.1 Emerging themes

The themes generated from the audio recordings were varied and honest from the carers. There was a general list of day to day activity from both men, for example visits to the doctor and dentist, visits from friends and family. Although some of this detail was recorded on the audio recorders the small diaries given to the carers were also full of these details. Details of their wife's dementia was also recorded from the point of diagnosis and also included the changes they had been coping with. However, both men were able to articulate thoughts and feelings and these themes are represented in the mind maps below.

The themes have been categorised into the two sections highlighted in the analysis section that differentiate the different issues being assessed in the pilot study, e.g. the effectiveness of using the recorder for capturing the informal male carers experiences and the richness of the data captured in those recordings. The quotes given show the Carer identification number, then the line numbers

from the transcribed interviews. This process of documentation has been repeated for all the quotes from the carers in this the study, in other sections.

Figure 5.3.1 Using Audio Recorder



Carer A found using the audio recorder very difficult for several reasons as the quotes below show;

"I'm not sure whether my previous recording took?" (Carer A2; 1-2).

"We've been away for a few days and there hasn't been much opportunity or inclination I should say perhaps to do any recording" (Carer A4; 3-5).

"No benefit to me" (Carer A4; 7-11.)

The main themes around using the audio recorder for Carer A appear to be his unfamiliarity with the recording device and how it worked, but also the benefit of doing the recordings for himself. This following quote demonstrates the strength of feeling he felt against this process. His dislike of using the audio recorder all too evident.

“From my point of view I’m afraid it hasn’t been a great deal of success; I’ve found it not a particularly helpful exercise in any way” (Carer A4; 6-8).

As an exercise in recording their caring experiences, all the carers including Carer C before he withdrew from the pilot study, expressed their opinion to me that they would have rather spoken or been interviewed by myself for the study. The quotes below clearly articulate their sentiments on this issue:

“If you have got anything (from the recordings) you wish to ask me or discuss I would be very happy to do so”. (Carer A4; 12-13).

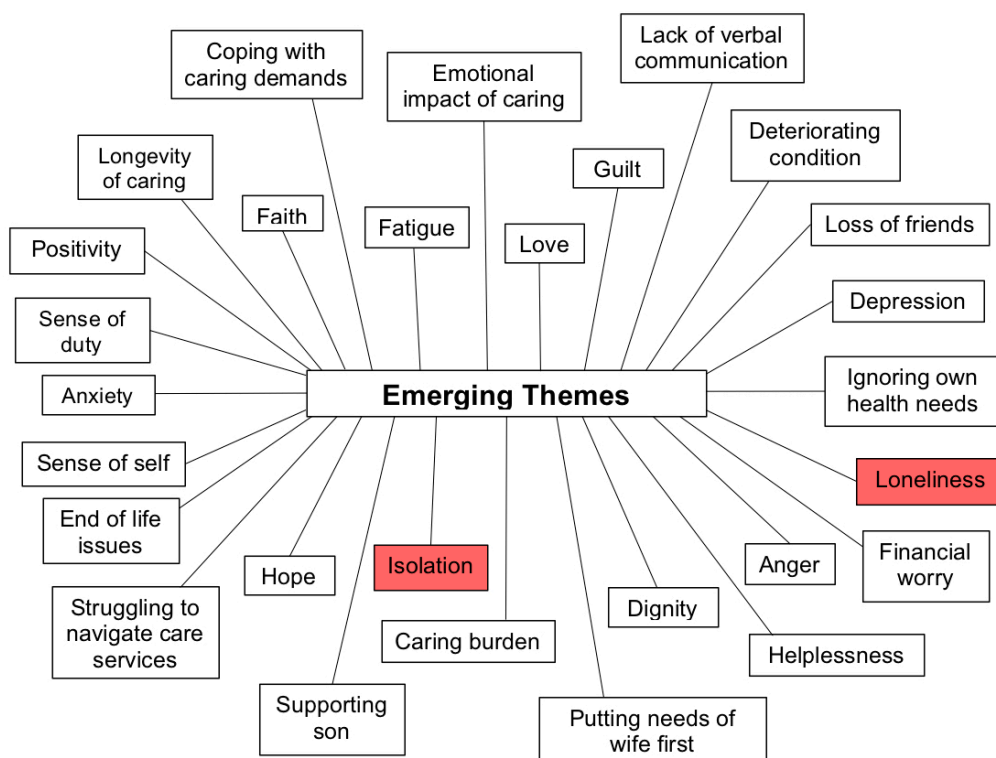
“I would probably have got more out of him if we had talked together” (Carer B end interview 14/10/14).

“Couldn’t get used to talking to myself. Would very much like to talk to me” (Carer C withdrawal interview 29/10/14).

The mind map below shows the emerging themes that demonstrate the richness of the data that the carers were able to verbalise. Despite their misgiving with the

process as a whole, the thoughts and feelings they were able to record were honest, moving and varied.

Figure 5.3.2 Pilot Study Themes



Six of the emerging themes have been chosen to demonstrate the richness of the data collected by the audio recordings from the carers. These six themes were chosen as examples of the in-depth experiences that the carers shared in this pilot study. There was evidence for all the themes as identified in the mind map above, the two highlighted themes suggesting that the issue of social isolation and loneliness for informal carers continues to warrant the further exploration as proposed in this thesis.

The first theme supported by the findings of the pilot study is the need for the carer to put the needs of his wife first.

“I’m finding I have to spend far, well all my time really, when H is awake with her, she gets very nervous immediately I’m out of sight”. (Carer A1; 22-24).

“At home I was providing 24/7 care, washing, dressing and helping v in and out of bed, helping her walk to and from the chair and to the bathroom as she was doubly incontinent” (Carer B; 4-9).

For the carers in the study continually caring for their wives meant that their own health needs were ignored at times. This second theme is supported here by the following quotes.

“It’s my own health, which I think I have probably told you has not been all that great for the last year or two” (Carer A1; 11-12).

“I have spinal stenosis, and a dropped right foot which limits my mobility, I’m not getting a lot of relief from the pain but see the consultant in a few months” (Carer B5; 72-77).

“It been difficult in the last few months with the onset of osteo-arthritis and rheumatoid arthritis and inflammatory arthritis in my joints coupled with the problems in my back with spinal stenosis” (Carer B22; 15-18.)

The third theme that emerges from the recording of the carers’ experiences was that of the emotional burden of caring.

“Still a bit limp today unfortunately this has quite a bad effect on H because whenever I’m not able to feel awfully cheerful she assumes she has done something wrong (his voice changes and sound tearful and upset)”

(Carer A2; 4-8).

“A new G.P. who is allocated to [Wife] I had spoken to him previously about resuscitation which was a difficult thing” (Carer B6; 7-10).

Both carers demonstrated a connection to their wives that they were diligent about maintaining in the presence of their dementia. They showed examples of love, shared activities, and non-verbal communication between them and their wives in this fourth theme.

“She seems to have got much worse, also her moods are a little lower and she is less inclined to be cheerful and is obviously feeling herself that she is in a more confused state which is a worry” (Carer A3; 7-10).

“I visit as I have done each day, I read poetry to her, I read short stories, I listen to music with her” (Carer B5; 48-49).

“I shall continue to see my love each day if I can” (Carer B22; 25.)

“A good visit today we didn’t do any reading, poetry, or music I had such a lovely reception from her today beautiful smile and her eyes sparkling”

(Carer B; 5-7).

As well as reflections on the role of carer for their wives and how they experience that role, the men in the pilot study also showed an awareness of their own sense of self in this fifth theme.

"I have taken her to stay with her sister today while I go out for a walk"

(CarerA3; 1-2).

"Lately we had two mornings with carers to give respite for me so that I could go to indoor bowls on Friday morning and also help at my bowls club for disabled people on Wednesday mornings" (Carer B4; 11-13).

The last theme highlighted here is the issue of social isolation and loneliness. These examples below are subtle in nature and do not demonstrate the dichotomy that the terms suggest. The quotes point to a complex mixture of experiences and relationships that together, suggest that the issue of social isolation and loneliness of informal male carers needs to be further explored and understood.

"The fact that she gave me the privilege of looking after her so intimately for all that time (he begins to cry) I don't know how I did it"

(Carer B1; 10-12).

"This is the first time (crying now) [Wife] will have been away at Christmas and we have to think how we manage that so we can remain together"

(Carer B12; 33-35).

“If I’m sat in the lounge I wake looking for V in her chair nearby and I realise that I’m dreaming and seeing her, and then I come back to normality but it’s just an indication of just how much I miss her” (Carer B24; 3-6).

These themes above begin to show the lived experience of informal male carers caring for someone with advancing disease at home that took part in the pilot study.

5.4 Discussion

Using the recording device was generally used with ease by the carers participating. They easily understood how to get the recorder to record, and passed no comment on the smallness of the buttons needed to operate the device. Carer A felt uncomfortable talking into the machine and getting no feedback. Carer C had tried to persevere with the audio recorder but found recording his thoughts and feelings too difficult to do, and he withdrew from the study. When I returned to collect the audio recording device he was very apologetic at not being able to take part in the pilot study and offered his time for me to return and interview him about his experiences.

For Carer B, speaking into the recorder and getting no feedback was not a problem for him as his wife had lost her power of speech and had not verbally communicated with him for around 5 years and so he was used to no feedback.

Carer A found it very difficult to record his feelings. The recording became a list of what had happened during the week, the plumber coming, and going to the dentist for example. For Carer B however, recording his feelings came much easier and the data was rich with emotion, thoughts and feelings. All the carers found using the audio diary an inconvenience because of the time it took up during their day when they were caring for their wives. All the carers expressed the view that talking to me would have been preferable to using the audio recorder. Whilst this would inevitably encroach on the time they devoted to caring for their wives it appeared that they attached more value to this approach than using the audio recorder on their own.

The richness of the data from the recordings of Carer A and B was both thoughtful and poignant. The themes generated from the recordings show a complex caring experience for the informal male carer. For both men, the needs of their wives were paramount and superseded their own needs in terms of interests and health concerns. Ensuring they maintained connections with their wives through shared activities and interests helped maintain their sense of self, role and the sense of self for their wives also. A complex caring role is evidenced in the examples given despite the small sample size. The issue of social isolation and loneliness was present in the accounts of the lived experiences of the carers caring for someone with cancer and /or dementia and as such justifies the continued in depth pursuit of this issue to increase understanding.

The findings from the pilot study suggests that those carers that took part found using the audio recorder uncomfortable in terms of fitting it into their day, but also

not having immediate feedback as you might in a conversation. They were able to use the device but would have preferred taking face to face with someone. The evidence presented however, suggests that the thoughts, feelings, and emotions that they experienced as part of caring for their wife's with dementia were verbalized during their recordings.

5.5 Limitations of the pilot study

A limitation of this pilot study is the small sample size. However, a small number of men using the device with the shared characteristics of the group of men needed for the main study, allows the usefulness of the device to be assessed. It could be argued that a further limitation of this pilot study was that it was conducted in a rural area and as such the results would not be generalisable to a more urban setting. However, this was a pilot study of the pragmatic use of an audio recorder for capturing the informal carers' experience of caring for someone at home. There is no evidence to suggest that those living in an urban setting would be more or less influenced by their geography, to use an audio recorder for the purposes of a research study.

5.6 Conclusion

It was agreed with my supervisors that due to the results above, the inconvenience of using the audio recorder and the men's preference for talking to someone about their experiences, the main study would not adopt the use of audio diaries as a means of data collection but that the study would be developed using semi-structured interviews. Recruitment for the pilot study had shown that the time taken to encourage participation in the study, as well as to highlight men

eligible for the study with the local GP's and Alzheimer's Society groups, meant that potential numbers of men for inclusion in the study were very low locally. It was agreed that the inclusion criteria needed to encompass a wider geographical area, and as such additional Alzheimer's Society groups and NHS memory clinics were included in the recruitment of men for this study. This change was agreed by a simple process within the Regional Ethics Committee protocol. Up to this point memory clinics and Alzheimer's society groups had not been approached in additional counties and towns. It was with hindsight that this was considered an oversight and offering the study to carers from a wider geographical area may have made recruitment more rapid. Thus these changes were made to the protocol and subsequently agreed by the Regional Ethics Committee.

6. Rationale for Main Study

Following the systematic review of the literature and the completion of the pilot study, the final study protocol using semi-structured interview method was developed to address the issues of social isolation and loneliness. This approach was adopted as the results of the pilot study showed that self-reporting by audio diaries were inconvenient and the offer of interviews were preferred by the proposed client group. All of the men in the pilot study identified that they would have preferred speaking to me rather than into the voice recorder.

The sample population for the study was men who were informal carers of those with advanced cancer and /or dementia in 3 geographical areas in the West Midlands. Study conduct in England would add to the knowledge of the experiences of male carers in the UK, influenced by the specific health care system, the National Health Service (NHS).

By in-depth exploration of the experience of loneliness and isolation for carers whilst caring for someone at home, we may begin to understand the nature and complexities of this aspect of care. Devising a research question however, that did not harm or pass judgement on the carers' perceived situation, was both thought provoking and valuable as it would allow the lived experience of social isolation and loneliness to appear if it was an issue for these carers'. It was agreed with the help of both supervisors, that framing the research question in a neutral way would allow the issue of loneliness and social isolation to emerge from the data if it was present, during the semi-structured interviews rather than asking about social isolation and loneliness directly. This approach to the formation of the research question removed any subjective judgement or preconceived assumptions of the carers' experience by the researcher. Also the demand characteristics of a narrow or specific question could prejudice the recalling of the caring experience by the carers interviewed. Following the pilot study, the research question for the main study, was developed.

7. Main Study Male Carer Experience (MaCE)

7.1 Research Question

How does caring for someone with advanced cancer or later stage dementia affect informal male carers' personal and social relationships?

7.2 Methodology

The methods used for the study were consistent with the phenomenological approach and directly followed the methodology in Section 8. The carers with the specific experience of caring for those with cancer and/or dementia were recruited to address the research question.

7.2.1 Inclusion criteria

- Male carers aged 18years and older.
- Carers caring for those with later stage dementia at home *or*
- Carers caring for those with advanced cancer at home
- Carers known to Coventry and Warwickshire GP's, Worcestershire, Coventry and Warwickshire, and Gloucestershire Alzheimer's Society, and Worcestershire, and Coventry and Warwickshire NHS memory clinics.

7.2.2 Exclusion Criteria

- Carers with a severe psychiatric disorder
- Carers who lack capacity to take part
- Carers who cannot understand English

7.2.3 Consent Procedure

Consent for participation in MaCE was collected by myself after the participants were identified by a third part, for example G.P or Alzheimer's Society group. Consent is the process by which researchers promote good practice and ethical standards, ensuring that those who enter into a research study are as fully aware of the reasons for the study, what is expected of them as participants in that study, and what the likely outcomes of that participation might be. Written information

about the study and who to contact if the participant is not happy with arrangements of the study is given prior to obtaining consent (Appendices 5 and 8). Local support networks were also identified to support those taking part. This process of information giving, questions answered, and fears being addressed, satisfies the good management and running of a research study (Whitney *et al.*, 2003; Grady, 2015).

7.2.4 Sampling strategy

As above, the population studied was a group of carers with the experience of caring for people with advanced cancer and/or later stage dementia at home. These men were recruited from participating GP surgeries and participating Alzheimer Society groups as agreed by the ethics committee's instruction. Information sheets, consent forms and support information was given at the recruitment stage. A variety of sampling techniques were considered. Random sampling of the local population was not used as randomisation is generally used to produce a representative sample of the population but not necessarily of those with the exact experience that addressed the research question. Therefore, maximum variation sampling (Langdrige 2007) was chosen to ensure that a variety of participants, with different ages, married or co-habiting, heterosexual or same sex couples, adult child/parent carers, English/non-English culture, for example, caring for people with similar conditions were accessed. This sampling framework also increased the likelihood that diverse and various participants would allow for commonalities and variances across the experiences of caring to emerge from the data. The variations and commonalities are consistent with the

phenomenological approach of the study, the ideals of dasein 'being in the world', and authenticity (Smith, 2007).

7.2.5 Data collection

Semi-structured interviews were conducted providing an in-depth exploration of the carers' experience. These interviews were conducted at 2-month intervals, 3 times to identify any temporality to the experiences recalled. The interviews were labelled allowing for the three interviews e.g. Carer 1 1a and 1b. This numbering allowed for the carer to withdraw from the study if desired and as such didn't assume that all three interviews would be completed. This was indeed the case for Carer 1. The quotes in the result section were identified in this way. Carers were asked to describe their experiences of caring for someone with cancer or later stage dementia at home. The carer was encouraged to describe some of the earlier stages of the illness as this information and experience was contextually important. By placing their experience in context with other life events and experiences promotes understanding of the value of that experience. A sense of temporality is established on which further experiential understanding can take place.

7.3 Data Analysis

The purpose of analysis of the transcribed interviews is to 'move from the particular to the shared' (Smith, Flowers and Larkin 2009). In other words, the individual carer experience is examined in depth to establish the meaning of the experience for that carer. The researcher maintains a commitment to understanding the participant's point of view and applies a psychological focus to

understanding the meaning for that carer of their experience (Smith, Flowers and Larkin 2009). This process is described by Smith (2007) as an iterative i.e. repeated, inductive cycle. Analysis of the data obtained by in-depth interviews involves flexible and creative interpretation to establish meaning and understanding.

The process of analysis, based on these phenomenological principles, is achieved by a series of steps:

- Reading and re-reading the text to immerse oneself in the data.
- Initial identification of key words, phrases and explanations - descriptive phase.
- Development of emerging themes – this begins the interpretative phase.
- Abstraction- 'putting like with like' (pg 96 Smith Flowers and Larkin 2009)
- Further analytical processes e.g. contextualisation, numeration and function enrich interpretation.

These steps were applied to the first carer interview and then subsequent interviews. This process was repeated for the second carer and subsequent carer interviews. Once all the individual interviews had been examined in this way and the themes identified these themes were then clustered across all interviews to establish commonalities and difference. Patterns across all the data were identified to achieve a greater understanding of the experience through more in-depth levels of interpretation. An example of these steps in the analysis of one of the themes, loneliness, is included in Appendices 9,10, and 11, each appendices referring to the different stages of interpretation highlighted in the Findings section, 12.

7.4 Data Management and Patient Confidentiality

The semi structured interviews with the carers were recorded on a digital recorder. Transcripts of these interviews were anonymous and the recordings were kept securely in a locked cabinet. Personal data of the participants were kept separately from the research data. This information will be kept for 10 years in line with data and research governance protocol at Warwick Medical School.

7.5 Ethical Considerations

This study the Male Carer Experience Study (MaCE) complied with and was reviewed by the NHS REC and the local NHS Trust R&D office Ref 15/WM/0181. This process facilitated thorough and robust attention to the design and to the conduct of the study. Compliance with data governance requirements was also thoroughly scrutinised. The principal investigator attended a full committee meeting to discuss and defend the research proposal. Twenty five members deliberated the proposal, the topic chosen for it's clinical and academic relevance, the methodology in particular IPA against other approaches, the recruitment strategy, data collection methods and dissemination of results. All questions were answered. The documents submitted can be found in the Appendix 6 of this thesis. All attempts to reduce any potential harm to the participants were undertaken with support highlighted at every stage of the study. My clinical experience in dealing with carers, families, and patients at distressing times enables a sensitive and timely approach to identifying and dealing with any potential distress that arises out of the in-depth interviews.

7.6 Confidentiality

The confidentiality of those carers taking part was maintained throughout the study, at all stages. Throughout the data collection stage the specific quotes and comments were not identified to individual participants. The use of 'Carer 1' etc. was consistent throughout the document to ensure no personal details were used. Through the careful use of general descriptors, for e.g. names of towns and professionals involved in their wives' care, no local knowledge could have been used to identify participants or groups.

7.7 Anonymity

Anonymity of the participants whilst in the study was safeguarded from anyone other than the researcher. Selection of the carers for the study was undertaken by a third party, (GP, Alzheimer Society staff and NHS memory clinic staff), and the names not revealed to the researcher until they had agreed to take part. Transcribed recordings, with personal details redacted, were kept separately from the demographic data of participants to strive to maintain anonymity.

8. Findings

The findings from MaCE are presented in this section – who participated in the study, who they were caring for and what the experiences of being an informal male carer was for them.

8.1 Sample Characteristics

The number of carer's contacted at each site was between one and three. A total of nine carers participated (Figure 6) which was acceptable with the phenomenological underpinning of the study.

Table 8.1.1 Recruitment For MaCE

Surgery	Carers contacted	Participants
Surgery 1.	10 dementia	2
Surgery 2.	4 dementia 5 cancer	1 1
Surgery 3.	2 cancer	2
Alzheimer's Society.	5 dementia	3
Total.	26	9

The nine carers who agreed to take part in the study were interviewed in their own homes with each interview lasting approximately an hour. The men were very open and honest during the interviews, with personal accounts and details of their experiences recalled with emotion and sadness. They were also generous with their time, some of the interviews lasted 90 minutes to two hours.

Carer	Participant Age (year)	Caring for Age (year)	Length of time with dementia/cancer	Care setting	Immediate Family of Participant
1	46	Father in law (Age not known)	Dementia and Cancer 18 months	Urban	1 daughter

2	53	Wife 51	Cancer 12yrs Recurrence 3yrs	Urban	1 daughter
3	70	Wife 69	Dementia 4yrs	Urban	1 son 3 daughters 9 grandchildren
4	77	Wife 70	Cancer 33yrs Recurrence 4yrs	Rural	1 son 1 daughter.
5	81	Wife 83	Dementia 5yrs	Urban	1 son 2 grandchildren
6	73	Wife 59	Dementia 6.5yrs	Urban	2 sons 1 daughter
7	66	Wife 66	Dementia 2.5yrs	Urban	1 son 1 daughter 1grandson
8	76	Wife 74	Cancer 26yrs Recurrence 6yrs	Rural	1 son 1 daughter
9	79	Wife 74	Dementia 3-4yrs	Urban	2 sons 1 daughter

Table 8.1.2 Carer Profiles for MaCE

The mean age of the carer was 69 and those they cared for 68, with a median of 73 and 69 respectively. Both carers and cared for were of a similar age and as they were elderly, the burden of the caring role is not insignificant. Further interpretation of the carer profile shows that despite all carers having children, they were involved to a lesser extent in the care of their mother, the caring role was seen as the husband's role first and foremost. All the carers identified their immediate family highlighting support or a lack of support in the interviews that followed. Across the interviews none of participants described the adult children taking a substantive role. The caring role undertaken by the carers, as seen in Table 3, ranged from 18 months to 6 years for those caring for those with dementia. The caring role for those with cancer, was not continuous and recurred at intervals as the disease changed, as the research interviews highlighted. This

is consistent with what is known about the trajectories of both cancer and dementia, the step-like progression of cancer as opposed to the steady decline over many years seen in dementia (Brayne *et al.*, 2006; Public Health England, 2013).

Carer 1 was a son-in-law, caring for his partner's father. He was interviewed once, but following that interview his father-in-law died. Despite efforts to contact him, he did not return these attempts and he was removed from the study. His initial data from interview 1 was included when generating the emerging themes from the interviews, at the descriptive stage of the analysis, but as the study continued his experiences of being a carer were lost.

8.2 Emerging Themes

Stage one of the analysis consisted of identifying the broad stroke themes that emerged from the text of the transcribed interviews. This stage of analysis begins the inductive process of examining and re-examining the transcripts. Reading and re-reading the transcripts ensures the researcher is fully immersed in the data from the carers, that they themselves become connected to the experience being recalled. This 'connection' allows for nuances to be seen in the data, emotional responses to the situation heard, and a respect for the carer and the cared for to be acknowledged.

The many emerging themes from the interviews, (Figure 8.2.1) highlighted the role of the carer. This stage of the analysis identifies common language, ideas, images and beliefs of the carers during their interviews. All of the themes

expressed by the carers were common across all the carers, however, sometimes the language varied and the description of the same theme varied.

The emerging themes from the interviews with the carers are illustrated on the mind maps overleaf and linked to the two elements of the research question (Figures 8.2.1 1, 8.2.2). The themes from the interviews that support the first part of the research question, personal relationships, were numerous and as such the diagram has been simplified for ease of reading. The complete number of themes have been included on a mind map in Appendix 11.

Figure 8.2.1 Emerging Themes (a)

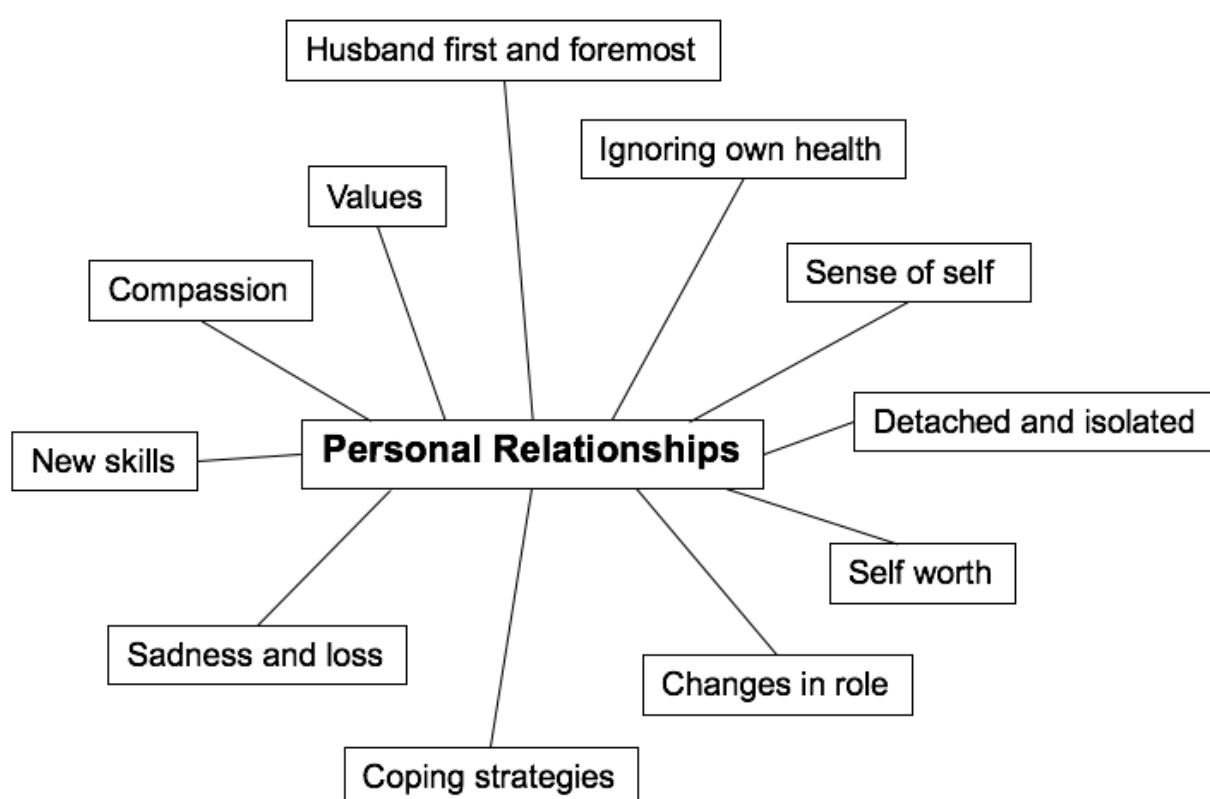
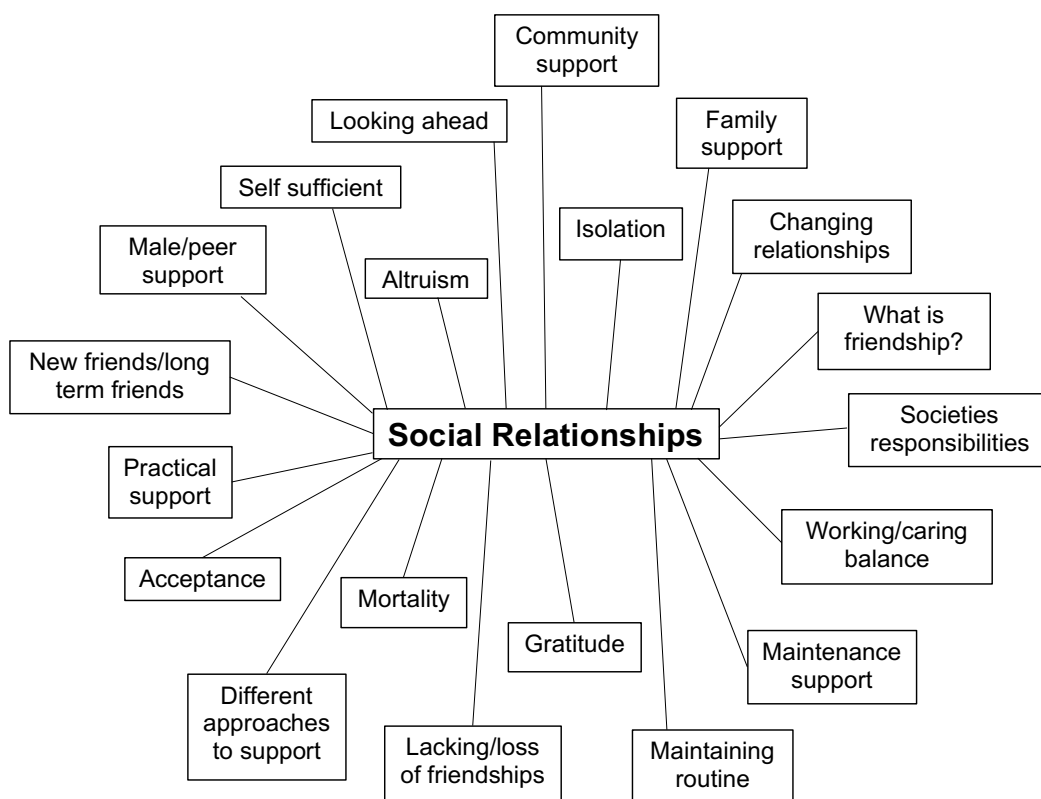


Figure 8.2.2 Emerging Themes (b)



Having identified a wide ranging complexity of themes to emerge from the interviews at no time did any of the men voice any regret or wish to 'walk away' from the caring role they now found themselves undertaking. A sense of carrying on and adapting to their role was evident.

8.3 Subordinate Themes

The subordinate themes emerged from the data by further examination of the emerging themes, clustering the emerging themes, and interpreting the themes using the IPA stages of analysis of the evidence presented by the men interviewed. By the process of abstraction, patterns were identified between

emerging themes encompassing all the nuances of the feelings and beliefs experienced. By using polarisation, oppositional relationships, and disconfirming themes, patterns and clusters were highlighted giving further depth to the analysis of the data. Contextualisation in the data allows subordinate themes to be grouped as 'life events' thereby identifying the temporal moment where they occurred. For example, the moment the carer and the cared for received the diagnosis, the time when they told their family and friends, and when the carer realised the loss that was to come.

"It's some 6 years since we were able to see um her mother, her father had died some years back. So this year has been a year of (pause) physical suffering for my wife, mental suffering for the people around her" (Carer 4;321-327)

"Yes, the thing I hate the most is that I can't talk to her about anything, she even has a job to get words out now, err you know she'll say something in the pub about, she'll point to something, and I'll say don't point, don't point, but she can't get words out to explain it." (Carer 5;482-485).

The clustering of the themes has the advantage of moving from the idiographic, the individuals experience, to the nomothetic, a general experience, and thereby understanding the carers experience. The clustering can then be balanced against the other interviews and any disconfirming themes identified. However, numerically all the themes were seen across all the interviews.

An important finding at this stage of the analysis however, was that the issue of loneliness and isolation was evident but not the all-consuming issue for the carers. It was present for the majority of the carers, $n=4$, but the descriptions were very subtle, not the dichotomy one would have anticipated based on the background to this study. This will be discussed further in Section 12.6.2. This quote below is an example of the subtlety of the experience of social isolation for Carer 3.

“So I have to rearrange the seats now go up in the balcony so there’s nobody behind you so” (Carer 3b;31-32).

Having combined the emerging themes, the subordinate themes (Figure 10) show a more complex pattern to the nature of the carer experience. These subordinate themes were developed from analysis and interpretation of the emerging themes into broader themes encompassing the nuances of the experience of the carers as identified across all the interviews conducted. This further interpretation of the interview data continues the IPA approach to understanding the informal male carer experience.

Table 8.3.1 Subordinate Themes

The Caring Role	The Individual	Role in Society	Relationships
Practical Tasks whilst caring	Changing sense of self	Changing relationships	Friendship
Multiple caring roles	Maintaining sense of self	Loneliness and isolation	Wider family/work/community
Complexity of caring role	Self as spouse	Being an advocate	Communication with others

Emotional caring versus practical caring	Ignoring own health needs	Valuing the positive side of caring	Support. Loss of control
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8.4 Superordinate Themes.

The superordinate themes that emerged were a further interpretive analysis of the previous themes in Figure 12.3.1, that distilled the essence of the experience of the men, interviewed, by interpretation of the researcher. Having moved from numerous emerging themes, (the idiographic), to less numerous subordinate themes, and then to less numerous superordinate themes, the essence or spirit of the experience is presented. A sense of the enormity of the experience is seen in the numerous themes generated at the initial stage of analysis. This sense of enormity, exemplified by the range of themes physical, emotional, spiritual and social, presented by the four super ordinate themes, begin to highlight the complexity of the carers' experience, at the final stage of data analysis of the data. This may begin to establish a wider understanding of the carers experience based on the individual nature of the evidence from the carers. This linking or embedding of one's own experiences to the experiences of all, is central to the phenomenological underpinnings of this study. The superordinate themes generated through the interpretative analytical process, and discussed in detail below, were as follows:

'when being with' becomes 'caring for'

'a sense of self'

'being separate together'

'connecting friendship with support'

Having moved from the idiographic nature of the men's experience, to the nomothetic, i.e. an interpretation of the experience seen across all the interviews, the last analysis gives a voice to the men's experience that will resonate with them all. It also establishes a wide ranging and encompassing interpretation that allows for the experience in its most complex form to emerge.

8.4.1 When 'being with' becomes 'caring for'

Superordinate Themes	Subordinate Themes	Emerging Themes
When 'being with' becomes 'caring for'	The Caring Role	Practical tasks; new skills, role of carer, challenges, information seeking, changes in role.
		Multiple caring roles; risk assessment, caring for grandchildren, caring for adult children.
		Complexity of caring role; burden, patience, dependency, frequency of support.
		Emotional caring versus practical caring; uncertainty, tension/anger, sadness, loss, trust, helplessness.

This superordinate theme comprises of the themes, multiple caring roles, complexity of caring role, emotional caring versus practical caring, ignoring own health needs, and loss of control (Appendix 13).

All the men interviewed recalled that the caring role was something to which they had adapted; the caring role was a practical one, helping with housework, personal caring, and managing the family home. For most of them this was an extension of what they did within their marriage relationship, and a sense of duty

was evident in how they described and undertook this role. Whilst the majority of the men described being able to cook and clean;

“I didn’t do what you might call big cooking then, but I wasn’t incapable of doing those things” (Carer 7;290-291).

The skills of cooking and cleaning for some men however, were a source of stress.

“... And after 5 years its um and I’m having to do jobs I never even thought of doing. I never knew how to work the washing machine, or drier, and um cooking and things like that.” (Carer 5;89-91).

All the men were able to help their spouses with personal care although they all identified that this was fairly minimal during the research time frame. For one man however, this personal care did not come easily and his frustration at the increasing need for his input was clearly evident.

“And I struggled to find the time to do it (his hobby) and because I had to put it down to do something else” (Carer 4a;189-190).

8.4.1.1 Multiple caring roles

All the men interviewed were parents of adult children and for two of the carers were also caring for elderly parents as well as their spouses, now commonly referred to as the Sandwich Generation (McNeil & Hunter, 2014). These multiple

caring roles for the men interviewed added a complexity to their experience with loyalties and commitments divided. For one man this conflict or tension of dual roles was a great source of disappointment as he felt his family should do more to support him both emotionally and practically.

“And um so [Wife] is very much tied up with her mother.

yes of course.

her mother and father are obviously both retired early 70’s I would think. But D is 82 and I’m 81 so um” (Carer 5;133-136).

For Carer 7 caring for an elderly parent identified conflict with professionals as the care for his father in law became more complex and end of life decisions more poignant.

“And went in and sister was on the desk, and I went up to her and said, AS family I understand you wanted us to come in, oh yes she said I’ll just have a word with you. She said now we’ve had to resuscitate your dad, this morning, so both M and I both said the same words at the same time, “on his paperwork it says he is not to be resuscitated” now this was 6 different times wasn’t it, because we kept a record of everything with your dad” (Carer 7a;258-262)

All the men were supported by their close family though this varied in terms of the type of support they received, the frequency of the support they received and their expectation of what they should receive. For Carer 2 having an elderly parent abroad added a distance to his role of caring for him both practically and emotionally.

“That’s it, even in Spain the traffic is bad and it gets its as soon as it gets dark and there’s flashing lights he gets he got flustered and that happened a couple of years back you know and uh I’d already decided (laughing) I wasn’t going to drive with him again luckily I don’t uh you know have very little to do with him because he’s so he’s so far away but I’m glad he’s not driving at all now because he could have had an accident in this country” (Carer 2;85-88).

Carer 7 was also involved in caring for a small grandchild and both he and his wife gained a lot of enjoyment from this and attached great value to the acceptance of the little boy to the situation, something they described as lacking within their own children.

“So we will go down and babysit that night, then we’ll go round early the next morning and we’ll have A all day, until mummy gets back from work in the afternoon, and he’ll have his party so his nana and grandpa, are going to be there so we’ll all be there” (Carer 7a;31-35)

As the adult children became more aware of the needs of their parents and the care their mother needed as her disease progressed, their relationship with their father changed. The adult children took the parental role in supporting their parents, and becoming more involved in decision making. This was readily accepted and acknowledged by the men interviewed and was seen as a support.

“They’re more protective I think

R... Are they

Yeah (pause) they’re on my case

Are they (laugh)

That's kids isn't it

Yeah they are looking after dad as well

Oh yeah yeah oh yes yes" (Carer 3;114-120).

For one carer however, having returning adult children to the home during this period of ill health caused tensions as well as providing support. Carer 4 was caring for his wife with cancer, his son with cancer, and for an elderly mother.

"The second experience with cancer (pause) was my son who had testicular cancer which again came out of the blue.

Um, that disrupted his life hugely um it came at a point of time which (pause) well it wrecked uh the sort of future he had hoped to map out for himself, and that that has caused um did cause uh considerable disruption to the family in terms of how to assist and help in the mental side of it, and then um (sigh & pause) my mother had another major fall, roughly the same sort of time"

(Carer 4;183-192)

8.4.1.2 Complexity of caring role.

Across all those interviewed a detailed narrative emerged of a role that was complex in terms of symptom management. For Carer 2 the symptoms of chemotherapy were cyclical and this knowledge helped both he and his wife cope with the situation.

"It was the second or the yes the second time when all of these nasty symptoms came in (pause) and I said and she was really down I said hang on they were exactly the same ones you had the first time, ahh, right so it and you got over those didn't you, and then when they the same very similar ones happened the third time she knew that they were going, it wasn't going to, cos she you know that second time she thought it was going to go on forever, and then then when I said no it eased off didn't it um, but it did and and so now we've got that up and down and so we're sort of into our cycle." (Carer 2a;327-335).

For Carers' 5, 6 and 7 the caring role involved the administration of existing medication for co- morbidities, and the monitoring of medication for the relief of symptoms.

"So um from that aspect I make sure she has all the tablets every day you know, normal things she has, she has about 6 in the morning, a couple at night, and um I make sure that she goes on the appointments on time I make all the appointments for her and stuff, err make sure she has a shower a couple of times a week, um things I wouldn't even have to she would have had a shower every day in the old days" (Carer 5;250-255).

"Um I've got all the ointments and stuff for her so, um but otherwise taking the tablets, I give them to her first thing in the morning these a couple at night time and everything's under control at the moment" (Carer 5a;467-472)

“Well certainly while you’ve had this medication, for the epilepsy, it’s really knocked you for six” (Carer 7a;591-592).

“Well this is it, alright J suffers from she’s got dementia, but she’s got diabetes as well, so she has to have tablets for that, I have to sort the tablets out, she started off on a 5mg tablet and err Dr at C centre, that deals with people with dementia, specialises in that, he put her straight onto 10mgs she was sleeping 17 hrs a day, I got hold of the nurse, who deals with it, told her and she put her back on 5. Put her on to 5 and she’s alright alright” (Carer 6;105-114).

For Carer 7 an emergency situation meant he needed to respond to his wife in a different way. His existing knowledge of first aid was vital.

“And I’m in the kitchen and I can hear this funny noise, so I come to the bottom of the stairs rushed upstairs cos M breathing had gone totally different, put the light on and she’s got a froth round her mouth, and she’s lying on her back, now we were both in further education, and we were both first aiders, so I immediately put her on her side, with a pillow so she couldn’t roll over, I’ve got to phone 999 but I’ve got to unlock the front door first cos I can’t be upstairs doing that and running to the front door, um and within what seemed to be minutes, it was less than 5 we’ve got and ambulance” (Carer 7a;314-321).

A picture of complex care can be seen as the men interviewed took on a role that they had little experience of, or education about, before their spouses’ diagnoses. For all the men managing appointments with professionals for existing diagnoses and current difficulties led at times to a picture of frustration and anger. The time

involved in chasing up appointments, asking for transport and explaining the difficulties their spouses have, led to a physically tiring role and added an emotional cost to the caring role for the carer.

The following quotes were an example of the complex role of the carers. For the presentation of the findings these quotes were placed in this section. However, they could equally have been an example of a loss of control or the continued ignoring of the carers own health needs. The complexity of the decision-making process for the carers interviewed is in no doubt.

“And another reason I had M come round was that because they’ve been telling me I ought to have some respite anyway, and err my son’s been on about it and um we decided that we’d try and get D a week’s respite” (R is crying)
(Carer 5b;17-20).

‘Do I need to see you again? And we both said we can’t make that decision, you know where we are with this journey um she said, well it’s up to you and I was thinking it shouldn’t be us making that decision’ (Carer 7b;37-40).

For some of those interviewed the physical aspects of caring for another was something they had to adapt to as the diseases progressed and the cared for became more limited in what they could do for themselves.

“If he’s got no clothes on I have to wash him I’ve grown up being in a sport environment seeing another bloke’s bodies so it’s no big deal to me so you

know so he can wash he's self, so I just so wash this wash that and wash this"
(Carer 1;286-287).

A sense of constant change in the situation was identified as the disease changed, their spouse changed, the carer had to change, and the family needed to adapt to a change in their supportive role. The interviews conveyed this constant sense of movement and as such identified the complexities of the care needed for those at home.

"She hasn't really she's hardly done anything, but in her mind she's been doing things which is important and yes so I just let her get on in it anything she wants to do things like that and I give her all the help but err it's very difficult because she, as familiar as she ought to be in the kitchen cos it was her kitchen, she can't find things, or she puts things away in different places unbelievable how you can't imagine how you suddenly find something and you're not looking for that and suddenly you're met by something else in the cupboard and how did that get there?" (Carer 5;116-119).

8.4.1.3 Emotional caring versus practical caring

For most of the men interviewed the difference between the physical and emotional aspects of the caring role were highlighted but not expanded on in any great depth. They acknowledged that there was an emotional support element needed but weren't able to articulate what this was for them. It appeared that carers were happy to adopt their new practical and "managerial" role towards the home and their spouse's disease, leaving the emotional support to family and

friends. One of the men interviewed described a deep connection with his wife as her dementia progressed, the focus of his care more emotionally led. The other men identified the consuming practical aspects of their caring role in comparison.

“The whole thing is emotionally challenging” (Carer 1;291).

*“Drumming fingers on the table. Staying positive I think yes cos you have to its almost a split you know how it’s it’s saying right yes being positive I think. Um”
(Carer 2;172-176).*

8.4.1.4 Ignoring own health needs

All the men interviewed articulated the effect their caring role had on their own health needs; sometimes they ignored serious health needs and worries.

“Well just over 15 weeks ago I had a heart attack, err I was at the hospital with D she’s had an examination or, she was going to the toilet a lot, and I suddenly started terrific sweating and pain down here, (motions to his arm), and we’ve got to get back I said, there’s something wrong with me, and I actually left the hospital to drive back home and then ring them back up” (Carer 5;161-165).

For Carers’ 5 and 6 a delay in corrective surgery for themselves was evident while they waited until the urgency of their own needs prevailed.

“I’ve got it all strapped up at the moment, I’ve got carple tunnel, and pain in both hands, I said you aint doing both hands together, (laughing) that’s bad enough having one hand um” (Carer 6;128-130).

“I’m struggling I need a back operation, which the guy told me the consultant said you could come out worse, so that was enough for me, i.e. wheelchair. I’d had to 20 years ago I thought no way can I risk that, and it does restrict me but um we’ve only got a small garden here at the back so it’s nice to potter about there” (Carer 5;219-223).

As the men in the study were the sole day to day carers for their wives, this delay in seeking treatment meant that they continued their role despite increasing ill health, pain, and discomfort.

The ongoing nature of the caring role meant that a lack of sleep, snatched meals, and a general level of stress, increased their likelihood for viruses and episodes of minor ill health, all impacting on their ability to maintain their caring role. Also the longevity of their role meant that for some, years of caring had an ongoing cost.

*“Yes. I’ve just been worried about R this week cos he’s been so poorly,
I’m alright.
you’re not alright
yes well boss, oh that sounds good me calling you boss,
but you really have got an awful cold,
I’m a thousand time better than I was last night” (Carer 7a;604-608).*

“And we’re driving down the road and I’m thinking my wallet is still on the table in here, or I haven’t got a coat on, and sometimes I don’t even come back for a coat because I just think I haven’t got the time to go back” (Carer 7a 35-37).

“When M is asleep, normally doesn’t take long, but again sometimes it can, um and I’ve got out of bed and I’m on the computer and done some e mails and various things, but that’s meant I’ve probably then sort of got in to bed at midnight. Um which is not a good thing” (Carer 7b;183-186).

“And um we find that we’re not really on the ball as much as I’d like us to be. So in a way that gets me down there just isn’t time for everything, and by the time I’ve got lunch together I’m pretty tired” (Carer 9a;154-156).

8.4.1.5 Loss of control

A loss of control arising out of the caring role took several forms. For the majority this loss of control was a change in lifestyle, activities, housing, social standing and for one a loss of geographical mobility. This wider picture of the provision of care for those with cancer was clearly verbalised by Carer 4, suggesting that the centralised treatment and care for his wife kept them geographically confined, and was seen as a loss of control of mobility to other parts of the country to be nearer family.

“So then then the question arises is the specialisation in these various cancer units different, different people different personnel, but in the provision in terms of the particular cancer that is being treated may not be dealt with as

adequately, or better. So movement is a problem, so that doesn't apply to many people except people who are still working and have jobs which potentially make movement necessary um so you come under an amount of stress and stress on the family etc. etc. etc." (Carer 4b;27-33)

Life style changes included a lack of opportunity for holidays due to treatment and appointments, and a curtailing of interests and hobbies as their caring role became more demanding.

"Well yes, we we're trying to book some now things are a bit uh (pause) bit more secure you know we'll try get some decent holidays" (Carer 2b;34-35).

Changes in housing meant a move to a smaller property and one more easily managed was essential for Carer 9.

"The fact that we had a pretty quick sale, within 6 weeks of it going on the market, in April it was Eastertime, and we had agreement or acceptance of an offer, in late May, found a property here, this one, tiny bungalow compared with our 6bedroom country house, which was a rambling sort of farmhouse, type of thing, but up in NH" (Carer 9;12-16).

For most of the carers managing the home, practical tasks, and personal care led to feelings of loss of control. For one carer the need for his wife to go to day care meant that professionals were now "in charge" of her care and his role as husband was usurped resulting in this sense of a loss of control.

She's in her own little world now, his B centre where she goes, um I don't know what they do there" (Carer 5;232-237)

The themes above multiple caring role, complexity of caring role, emotional caring versus practical caring, ignoring own health needs, and a loss of control highlight the nature of the superordinate theme 'when being with becomes caring for'.

These quotes are not exhaustive and whilst they have been split up to enable a clearer picture of the caring role to emerge, in reality all of them impact on each other, all of them happen simultaneously, and all of them are experienced at some time and to some degree by those interviewed.

8.4.2 'A sense of self'

Superordinate Themes	Subordinate Themes	Emerging Themes
'a sense of self'	The individual	Changing sense of self; duty, self-worth, loss of status.
		Maintaining sense of self; purposeful role
		Self as spouse; selfhood in dementia, husband first and foremost, open and honest relationship, what is marriage?
		Ignoring own health needs; delaying surgery, carrying on when ill, not getting adequate rest.

This superordinate theme encompasses the changing self, maintaining self, and self as spouse (Appendix 13). These concepts of ourselves through behaviour allow others to examine how we see ourselves, how our role is defined, and what values and beliefs drive our behaviour. We bring this sense of self to all our experiences and as such the men interviewed were able to articulate how they had changed in their caring role, what they had maintained within their role, and

their sense of being a spouse in their caring role, in all but one case. Carer 1 was caring for his father-in-law and was able to identify the issues for him as a son-in-law.

Figure 8.4.2 Self As Central To Experience

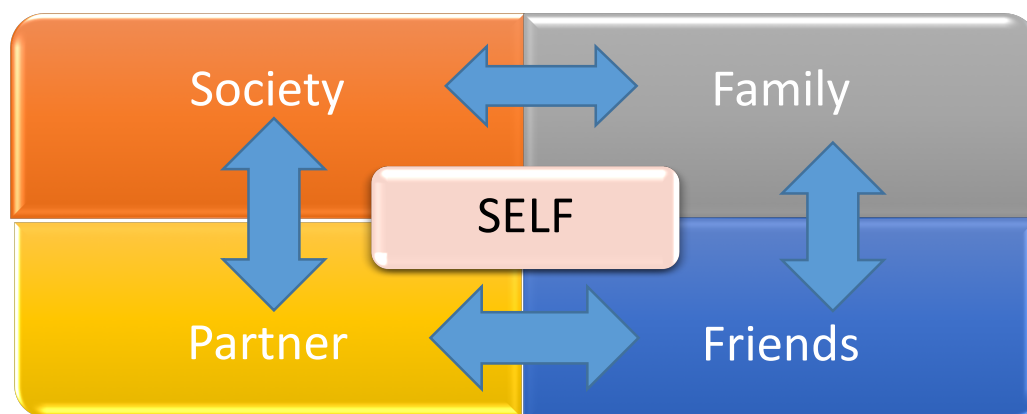


Figure 8.4.2, devised by myself, shows how experiences are linked to each other and relationships, each one influencing and moderating the other. The boundaries between all these elements are fluid and therefore all our experiences are influenced by the interactions that happen between all of them. In this way our sense of self is influenced, governed by, and changes due to these ongoing interactions.

8.4.2.1 Changing self

All the men interviewed were able to articulate changes in themselves that had taken place as they took on the caring role for their wives. They gave examples of skills and experiences they had brought to their caring role.

"I didn't do what you might call big cooking then, but I wasn't incapable of doing those things" (Carer 7;290-291).

They also recalled skills they had to learn for this new role of caring for their wives.

"Um I used to do the washing up because S had catered for us as a family, she'd done the shopping, she'd done the cooking basically, and I wasn't a dab hand at cooking, but it was always my job to wash up. Now of course it's a reversal of that" (Carer 9a;28-30).

"Finally this weekend when I started to do a bit of cleaning, the place to what it used to be is a pig sty" (Carer 5;150-154).

They also were able to identify what sort of a carer/husband they wanted to be as they cared for their wives.

"I was put on here to help people and it's who I am" (Carer 3a;406).

"But you've got to be forthright and just say it as it is because there's no point saying would it be possible for you to because if you say would it be possible then the chances are the answer could be no. and I don't want a negative answer" (Carer 7a;566-569).

They were changed by caring, changed by being a carer and this affected them as individuals in their world.

“And it has it’s been it’s a whole new learning process for both of us”

(Carer 7;704).

“It does mean we’ve got to be, I think we’ve got to be quietly um, what’s the word, just not go at things too much, in a rush. And I must try and be aware of that cos I tend to do that” (Carer 9;288-290).

“One time I thought carer was predominately female, of the nursing profession that went into people’s homes’ 4 times a day, to get them up and give them their tablets, like people did with your dad..... there were very few men involved in that at all. They were predominately young, teenage girls who were over 16, who were new to nursing” (Carer 7;462-469).

For the majority of those interviewed the greatest change was in the practical tasks they now took on. However, for a few, the change in what mattered to them as their caring role intensified was poignant and moving.

“Our Christmas had a bit of a cloud over it not only through, it’s not the same now with D, I’ve lost interest in things like that now” (Carer 5;113-114).

8.4.2.2 Maintaining self

For all the men interviewed maintaining their interests and hobbies was important for them. These value-based activities pre-caring role, were very important to the carers to maintain their sense of self. Maintaining them however, in the face of

increasing demands on their time and energy was a source of conflict and frustration for some. Here are some of the examples that they gave.

“When your down I mean maybe you don’t get down but when you’re down or fed up how do you how do you manage that?

With music, music is a cure for most things” (Carer 3a;271-275).

“But something caught my eye last week, uh it (pause) awoke something which was in my memory. I’ve tried to find time the last week to just chase up this particular thought because the article I was reading stopped and I thought yes I can see why because that’s, because those 3 thing are only used at sixth form level, but it could go on, and I thought well if went on what’s the next step after that? Now I got to the 4th, the 5th, the 6th, and the 7th, and the 8th step and I struggled to find the time to do it and because I had to put it down to do something else” (Carer 4a;183-190).

“I mean my retirement interests are not going to the golf club and playing golf or anything like that, cricket I played until I was 50 um but now I’m I read, I read quickly and voraciously, um which is a sole occupation, um I paint”
(Carer 4b;347-350).

“When I go to my model railway I’m on the committee now as well, we go on a Wednesday meeting, once a month, but that’s not as long as the normal meeting. Now me sons at home so he comes in and stays here so she’s got someone looking after her” (Carer 6a;169-171).

8.4.2.3 Self as spouse

Eight out of nine of the carers interviewed were married to those they cared for. The men identified a blurring of the role and responsibility of marriage when faced with their caring role in ill health. They found it difficult to distinguish between the two roles at times and the 'caring' element was definitely how they identified with themselves as a spouse.

"Assistant is the wrong word but it's more along the assistants you know assisting rather than caring because it's just doing those things (whispers)"
(Carer 2;153-156).

"We've been married 50years so we are a partnership" (Carer 3;129).

"We have our own little unit" (Carer 3;209).

"She indoors he outdoors" (Carer 4;570).

"But I'm not worried about the word carer as me being with a label, um I prefer to be called husband carer, because I see my husband role as what I am, by virtue of being married to M, but the word carer needs to be there, because to other people it shows that M has to have some care" (Carer 7;470-473).

"Husband first and foremost" (Carer 8;104).

"I'm your eyes and you're my hearing and really that was it" (Carer 9;221).

As one can see the role of husband superseded any title of carer with all the men seeing being a husband as their primary role. They did not separate the two roles and their sense of self identity remained with their sense of spouse.

Further analysis of the interviews revealed an area of the carer experience that was difficult to place in the themes already mentioned. These quotes seemed to suggest that the carers were also thinking of their experience in a wider sense than the individual sense of self for example their roles and responsibility and self-identity. It seemed to me that they were trying to articulate a sense of the wider picture of caring, the complexity of the experience they were part of. These quotes below suggest this.

“A week um he’s such a worry all the time even though we’re away on holiday it’s you are still thinking you’re talking about it all the time it’s dominating our life”
(Carer 1;150-153).

“She had certain had blood transfusions after chemo so it brings back all those horrible memories and you know like she was 55 he’s 85 and I think (long pause) and those memories are still there aren’t they of course you try to bury them but err when you’ve got things like this happening it sort of brings them back out” (Carer 1;345-350)

” I’m sure there are people out there who you hear about these people who they possibly haven’t had children or who haven’t much family and there’s just the two of them and that must be it must be hard having to stop and give up work, to help must be hard” (Carer 2;274- 277)

"She said oh you've been put here to help (pause) so I felt fearless now"

(Carer 3;274).

"If you get stressed out you can read that and think well

Yeah yeah do you find yourself reading it?

Oh yes yeah brings me back to Earth" (Carer 3b;131-133).

"Um, I always seem to be an observer rather than a, a joiner, maybe that's a part of me. I am (pause) very much an observer of life" (Carer 4;503-504.)

"Um, so there's a bit of tension which expresses itself of course in short temper and um etc" (Carer 4a;23-24).

'I tended to rush round and get everything done while I was there, I always used to go back to the church where it was running and I'd sit and have a coffee and a cake, um and talk to the people that were there, and they were lovely, and I did actually wind down' (Carer 7b;539-542).

"We find that we're not really on the ball as much as I'd like us to be. So in a way that gets me down there just isn't time for everything" (Carer 9a;154-155).

"They do and I'm a bit anxious about the longer term future, not immediate future, but we haven't done any planning for our death or anything pertaining to getting old and infirm" (Carer 9a;273- 275).

The themes above, changing self, maintaining self, and self as spouse make up the superordinate theme of “a sense of self”.

8.4.3 ‘Being separate together’

Superordinate Themes	Subordinate Themes	Emerging Themes
‘being separate together’	Role in Society	Changing relationships; togetherness, changes in role, expectation of ageing.
		Loneliness and isolation; lonely, isolated, maintaining connections, loss of spouse.
		Being an advocate; advocacy, judgement, role of husband.
		Valuing the positive side of caring; positiveness, values, humour.

This section of the findings show how the men made sense of their relationships in the face of their caring role (Appendix 13). All the men described a change in their relationships with their immediate family.

“I am finding it increasingly tiring, I have to admit that. And my son sees it and he’s he’s taking more and more on his shoulders which he shouldn’t have to because he’s got his own stuff to do” (Carer 4a;120-122).

“It’s just lucky if you’ve got daughter and son to you know take some of the load off me there” (Carer 4a;157-158).

“Yeah good as gold, they’d come down regular and they’re on the ball they’re in touch with Dr. B” (Carer 3;51-55).

They also highlighted changes in their relationships with their spouse. For some this was a loss of communication.

*“Do you have conversation with her, are you able to (pause)
It’s pretty basic” (Carer 3;72-73).*

*“Yes, the thing I hate the most is that I can’t talk to her about anything”
(Carer 5b;482).*

For other carers it was a loss of shared activities and interests,

*“But she gets bored of it quick, and err that’s why it’s easy to go from B to K and so what we do is have a couple of hours at one then drive to the other one”
(Carer 5b;172-175).*

“We can’t play Scrabble anymore, that is a sadness cos we always used to enjoy Scrabble, we have tried once or twice” (Carer 9;78-79).

There was also a loss of the partnership or intimacy in the marriage for some couples.

“From that point so we’re talking 2008 (long pause while he gets the date right), we have not indulged. That leaves pressure on a relationship I would think anywhere” (Carer 4b;41-43)

“We had a good relationship, a good and loving and warm relationship um (pause/sigh).” (Carer 4;90-91).

This loss of partnership with their wives’ was a source of sadness to them all and they all took enjoyment from the moments they had together however fleeting and short lived in some cases.

“We go out every night to the pub I think I told you, still do that, that’s a highlight” (Carer 5b;159-160).

“No I like this Wednesday, it’s err we have a day together still” (Carer 5a;525).

8.4.3.1 Changing relationships.

Their relationship with their spouse was changed to the greatest degree, by the practical tasks they now undertook, and the emotional cost of caring for someone with a terminal illness. All the men interviewed were parents to adult children and this relationship also changed. Their ongoing parental role continued with support for them and any grandchildren, but there was also a changing of role where the adult children took on the role of parent, making decisions for their father, and influencing the care needs of their mother.

*“And you’re in it together as it were do you agree and
 oh yea oh yea
 you’re agreed on a plan for P... care
 yea yea totally a hundred per cent together on it I know it’s her
 dad but she knows I’ve his best interests at heart so um yes”
 (Carer 1;395-399).*

“If she says it once she says it a dozen times while he’s here, he’s only here 10 minutes, but err he accepts all that. (Long pause) and of course we’ve both got power of attorney over her now, and err what I’ve had to do as well, I hate this side of it” (Carer 5a;404-406).

“From then on life changed. We swopped roles, because she had done all the cooking and stuff, I had to take charge eventually” (Carer 9;25-27).

“Something I can mention that is fairly common place is that I read things to her, because she can’t read, not fluently anyway, it takes her ages to get through a page of a novel or anything” (Carer 9a;9-11).

*“There are sometimes when I’ve raised my voice at you because I’ve said it about 5 times and you said “well I didn’t hear you”, and I said well you told me three times you didn’t hear me that’s why I’ve raised my voice, and now your saying I’m shouting and it’s getting a balance between that um”
 (Carer 7;480-483).*

8.4.3.2 Loneliness and isolation.

When devising the research question a direct question asking about loneliness and isolation was avoided, as it was thought that this topic would come out of the interviews if it was present, and also minimize any potential distress or anxiety for those being interviewed. This approach ensured the demand characteristics of a direct question did not cloud the carers retold experience. However, as the relationship with the carer developed over the research time frame, this direct question was asked of some. The developing relationship between the carer and the researcher allowed for a more direct and probing interview as the feelings of trust between the two developed. All those asked expressed surprise at the question and denied feeling lonely or isolated. As some of the quotes below identify however, some of their ways of coping with caring for their wives shows isolation as a potential tool for managing this caring role.

“Well exactly yeah yeah we do things together so she likes walking up H Woods

she’d spend hours up there

Could she yeah it’s nice up there isn’t it

Yeah

Its part of the part of the area that’s pretty and do you meet many other people

up there walking?

Not really no because we tend to go in the mornings” (Carer 3b;322-328).

“Well I go out anyway so I go to work so that my that’s my contact with the

outside world

Right okay

Otherwise it would be a bit limited so you have to get out" (Carer 3a;57-60).

Carer 5's expectation of aging and retirement meant that a decrease in activity, and interaction with friends was to be expected.

"I don't feel lonely no; I think you've got to remember our age now you know"
(Carer 5;217-223)

"I hear all about my son and his game you know he plays every week, I know where he plays I know every hole he plays cos I've played them all a hundred times myself so I can picture these situations, so I'm happy about that. It's part of growing old isn't it, I suppose. (long pause)" (Carer 5;514-518).

"But it's certainly true about that you lose friends, because you're not socially acceptable really" (Carer 5a;289-290).

For Carer 6 he equated contact with friends as the reason why he was not lonely. "caring has sometimes been described as a lonely occupation or a lonely job if you like. Would you describe it like that?

meself I wouldn't because I've got a lot of friends around" (Carer 6;196-198).

"When I got home, J didn't want me to go anymore so I had to phone them up and cancel them, the other three sessions" (Carer 6a;130-131).

8.4.3.3 *Becoming an advocate*

All the men described the difficulties with becoming an advocate for their wives and struggled with the taking of control when the dementia demanded it, for instance taking control of their wife's money. Upholding their wife's wishes was very important for the men and accessing services was the most often source of the advocacy needed.

"As long as I can keep going here I will look after her. If she doesn't like what I'm doing, if it's something I've made or cooked, she'll tell me, probably throw it at me but um" (Carer 6;226-228).

"You have the right in the morning to decide on jewellery what you want on, and we have great fun in you deciding" (Carer 7;668-669).

"Going back to how we've coped um and things with us as a couple, um yes M always went to the doctors on her own, there was no need for me to go in, now I go in every time with her um because then she's got support when she's in there, she knows I'm fighting from her corner" (Carer 7;273-276).

8.4.3.4 *Poetry as a source of support*

Two of the carers gave me a poem at the end of the research time. Carer 3's poem below, shows him making sense of his wife's dementia by him putting himself in her shoes. He found this poem on the internet and gained a lot of support from it.

"If you get stressed out you can read that and think well

Yeah yeah do you find yourself reading it?

Oh yes yeah brings me back to Earth" (Carer 3b;131-133)

'Do not ask me to remember:

Don't try to make me understand.

Let me rest and know you're with me.

Kiss my cheek and hold my hand.

I'm confused beyond your concept.

I'm sad and sick and lost.

All I know is that I need you to be with me at all cost.

Do not lose your patience with me.

Do not scold or curse or cry.

I can't help the way I'm acting,

Can't be different though I try.

Just remember that I need you,

That the best of me is gone.

Please don't fail to stand beside me,

Love me 'til my life is done. '

This poem is an example of the advocacy Carer 3 takes on for his wife. By acknowledging her needs he is making sense of her situation. This is an example of perspective taking, being in the shoes of another, the essence of advocacy for this carer.

For Carer 5 the poem below is one he wrote from his wife's account of her feelings about her dementia. The empathic pain he demonstrated when giving it to me, crying for several minutes, is an example of advocacy bringing pain and connection with his wife and her dementia. He wrote this poem in capital letters.

WHY LORD, WHY ME?

YOU'VE TAKEN AWAY MY MEMORY.

HOW CAN I MEET MY FAMILY AND FRIENDS'

WHEN I DON'T KNOW WHO THEY ARE OR THEIR NAMES.

WHY LORD ME?

I TRIED ALL MY LIFE TO HELP OTHERS WILLINGLY.

IS THIS HOW YOU REWARD ME?

WHY LORD ME?

I CAN'T REMEMBER A BIRTHDAY OR ANNIVERSARY

OR PLACES THAT I'VE BEEN OR PEOPLE I'VE MET.

WHY LORD ME?

I DON'T WANT MY FAMILY AND FRIENDS TO REMEMBER ME LIKE THIS

I WANT TO BE REMEMBERED HOW I USED TO BE.

WHY LORD ME?

The need to show others what she was experiencing was important for this carer at a time when his wife could not do this herself. This was an emotional poem to read and shows the strength of feeling felt by Carer 5's wife, that in turn was experienced by him.

8.4.3.5 Valuing the positive.

For most of the carers interviewed there were times when positive aspects of their caring role were experienced. This was a sense of pride in the way they undertook their caring role for one carer, the continued enjoyment of shared activities however changed, and the time they had together. Despite three of the carers continuing to work outside the home, as well as their caring role, this positive attitude towards those they cared for enabled them to carry on caring in the face of continued change.

“Well I think the most positive part is that he’s still here. Um and he’s still pretty Compos Mentos um because I am absolutely convinced that if it wasn’t for me looking after him he’d be dead” (Carer 1;323-325).

“It’s alright good did you share any other likes (pause) in the years gone by Gardening which we still do” (Carer 3a;317-319).

“Well strangely one of the strengths of what’s happening is having the children at home” (Carer 4a;293-294).

“Subtitles, now I relish sub titles, but S can’t um she can’t read the words on the screen quickly enough anyway. Um so she’s better on dialogue so we sort of complement each other in many ways” (Carer 9a;61-63).

These themes identified above, changing relationships, loneliness and isolation, becoming an advocate, poetry as a source of support, and valuing the positive, are the themes that make up the superordinate theme “being separate together”.

8.4.4 ‘Connecting friendship with support’

Superordinate Themes	Subordinate Themes	Emerging Themes
‘connecting friendship with support’	Relationships	Friendships; maintaining connections, loss of friendships, new/old friends.
		Wider family/work/community; local community, hairdresser, church, support of work colleagues.
		Communication with others; men versus women.
		Support; receiving of food, taking to hospital appointments, telephone calls versus face to face contact.
		Loss of control; disappointment, handing care over to others.

This superordinate theme was made up of friendship, wider family/work/community, communication with others, and support (Appendix 14). For all the men interviewed the social relationships they enjoyed with friends, neighbours, and the wider public enhanced their caring role and was deemed very important for them to maintain. Whilst maintaining these relationships was difficult during this time of ill health and reducing capabilities, all those interviewed valued these connections and interactions. For some the increase in telephone contact with friends was supportive, for others this loss of face to face contact

was a sadness. Whilst maintaining friendship and support for themselves the carers interviewed also maintained these relationships as much as they could for their spouses.

8.4.4.1 Friendship

Support from friends for the men interviewed was varied and frequent. They described practical support, i.e. food parcels, as well as the opportunity for talking when needed.

“It hasn’t happened so much this time but last year when because it’s a paradox I think we’ve got that many friends there will be lots of people phoning and one night I got so (whispers) fed up because I got home (normal tone) and there was two phone calls waiting on there and I looked and I wanted to cook my dinner and I finally sat down and finished at 9 o’clock at night because I didn’t like to leave phone calls I think I spoke to about 6 different people that night (laughing) um an I thought well just look at the answer phone and don’t answer it” (Carer 2;86-93).

Attending appointments and treatment was something taken on by friends for two of the carers.

“I think her three friends I owe a big debt and she owes a debt to they provided tremendous support to her, and other friends” (Carer 4b;115-116).

It was also highlighted that the loss of friendships and family contact was felt very acutely by some of the carers.

“How have J’s um friends reacted to her dementia?

Er really fine they all understand

Yep, have they been able to come round as they did or

Er probably not her family and brothers and sisters have kept away

Right

They can’t really cope with it I don’t think” (Carer 3;201-207).

“Don’t want things to look worse when people we know ermm I would expect them to enquire but they don’t. I think I mentioned to you in the first time instance we met, that we went to a lunch, I don’t remember why we were invited, in the early days of her Alzheimer’s, I think it was around Christmas time, a couple there had been involved for a few years, he said “R you’ll find all your friends won’t want to know you and your family won’t want to know you either unless they want something” and well we haven’t got a lot of close family round here so, that didn’t occur, so the friend situation he’s right. People who were very close to you, have regular holidays, don’t want to know (R is crying)” (Carer 5b;438-447).

“Well we haven’t made friends here to go out with or anything” (Carer 5;179).

It was also highlighted by carer 5 and 6 that new friendships could be made at this time and these were valued just as much as longer term friends.

“You know but as a couple we’ve um got to know there, we didn’t know them at all, very friendly couple, and have got their own problems actually as well, their partners and um I said if she’s spoiling your night “oh no don’t ever say that and that’s nice isn’t it. (R crying)” (Carer 5b;187-190).

“We’ve got friends, very good friends, I could call on as well, are they long term friends, friends you’ve known for a long time? well one of them is, he’s only round the corner, um they’ve said that err, we’ve known them for a good many years, we had allotments together, but err I could call on him. Another friend we’ve met we’ve only speak 5 10 months, well he lives over at B just outside of L. So I could call on him as well if necessary” (Carer 6;38-44).

A sense of shared history and experience was also needed in ill health to sustain the carers.

“Here maintaining those relationships is by telephone and very occasional meetings because they’re spread out through the breadth of the country” (Carer 4a;236-240).

“Um we are lucky that we have got friends that understand” (Carer 7b;603).

8.4.4.2 Wider family/work/community

Wider family support was varied for those interviewed. Geographically scattered family meant that for some visits were less frequent than for others. For Carer 9

it was apparent that his siblings and cousins understood his wife's dementia and attendant consequences of her need for care, and were proactive in their support for him enabling him to have time away to pursue his interests and support networks. For Carers 5 and 6, wider family support was not forthcoming and this was a great sadness, sense of frustration and anger for the carer.

"To give R his credit nearly every evening when he leaves work he calls in on his way home to see her so see his mother and she likes that. Err regards to grandchildren to be honest I'm disappointed in my grandchildren"

(Carer 5;104-106).

For those three carers that were working both full and part-time, the support of employers and colleagues was acknowledged and valued.

"The individual support I got was superb from where I worked"

(Carer 4;126-127).

"And people have been in the same position (pause) chaps that I work with their parents had erm Alzheimer's so they know exactly what's happening"

(Carer 3b;345-350).

"But no the people we talk to on a regular basis um have been more supportive, um and offering their services and people turn up with a cake or flowers or something like that. Um but no we've got some people ask after and some people um some people particularly work it's let's stop asking (pause) their um"

somebody says and "how's the family" and you say "well I don't like to say but" "Ah huumm" well I'm sorry to hear that" and never mention it again. Whereas other people are very nice to me and ask so you have to but our friends know that and I don't think they've changed at all." (Carer 2;248-256).

For all carers interviewed, the need to work was important to maintain normality at home in terms of routine, continue to provide an income for their spouse, and continue their self -concept as provider and husband. For Carers' 5 and 9, the support of the local community, the hairdresser, the local church and neighbours meant that a feeling of acceptance of their wives was experienced.

"Mostly helpful mostly helpful. Um have there been times, no I think um if there's a church coffee morning, in fact we always drop in for coffee"
(Carer 9;212-213).

8.4.4.3 *Communication with others*

Communication with others was something that the men identified as difficult in most cases. They didn't want to burden others with their troubles at home and only responded to direct questions when asked how things were. Most of the men highlighted that women asked after their wives in the work and social settings, the men preferring to talk about their shared interests with other men. For Carer 7, educating others about living with dementia was central to his caring role and both he and his wife travelled extensively whilst she still could, talking to groups and attending seminars.

“Yes there’s a couple of women who I work with who are I think women are a bit more responsive they are able to be a bit more that way so um they still ask so I’ve no doubt they’ll ask when I go back tomorrow and they’ll be pleased um so um but yes your right um everybody else it’s ok it’s probably easier that way.”

(Carer 2;55-59).

“As I think I’ve said before its usually the the women at work who ask um but they they ask in a nice way and its nice, I think it’s almost a therapy to be able to (pause) recount to somebody just what the latest news is, it’s because its, I don’t know it just seems to be uh you know you’ve told somebody so it’s done and uh but uh yeah um and friends and family that’s um helpful, you know it’s just um it’s just nice to talk to them.” (Carer 2b;54-59).

“It’s just talking for me I guess it’s helpful in a sense.” (Carer 4a;447-448).

“[friend] was talking about her mum, and she said mums been diagnosed with Alzheimer’s and I said well [wife] got it. And there was no shock or horror on their faces they just said how are you coping with it, sit down with us and we’ll have a good talk, so you don’t feel that you might be doing something”

(Carer 7;800-804).

“There is one thing that males of the species and now I talk with, luckily M has got 4 ladies who are also doing the cognitive therapy things, and as husbands we’ve sort of sat and nattered, and they say things like “how do you cope with err getting dressed and that?”. (Carer 7;635-638).

8.4.4.4 Support

Support was a term that all the men interviewed used extensively. It was used interchangeably to mean friendship and practical support. Separating the two terms was not easy for the men and yet there was a difference, it seemed, by the examples they gave. Also knowing that there was professional support 'out there' was helpful to a couple of carers who felt they might need it in the future. Whilst five out of the nine carers interviewed accessed support for their wives i.e. day care and respite care, none of them accessed formal help for themselves. The support they did access was practical consisting of weekly cleaners, and help with heavier cleaning and gardening jobs.

"We are very fortunate we've got bags of friends and we've got a nice circle of friends and as soon as they found it had come back they said and a lot of them the wives work part-time or not at all and most of them can drive some of them say well I'll take her as long as it's day light or something like that we are very fortunate and that's why I can go to work" (Carer 2;50-54).

"Although there are still people who um you know asking they this it's not of that frantic extent probably because it's the second time around but we've still got the support so we still feel we have the same sort of support so it's not people leaving us" (Carer 2;95-98).

Peer support for Carer 3 was very important and despite the informality of it, he enjoyed the interaction with the other men he came across in the supermarket.

"Left at 9:30 do the shopping until tills open at 10 the same faces

Is it

Yeah it's like a little club an old boys club

(laughs) Oh right

It's an interesting way of looking at it

Yes, I'm sure

See fellas all round doing their shopping

They're doing their shopping

Might be the same I don't know, we have a little chat as we go around

Yeah I'm sure

We all get there for quarter to 10

(laughs) You're all ready and waiting" (Carer 3;325-327).

For Carer 4 the support that he and his wife accessed was different. He preferred passive almost unspoken support from those who knew what was happening, but as a group of work colleagues, they didn't want to talk about his wife's cancer.

"At that time did you have any support, you said the ladies went off were their

other halves you know did you sort of form a little support group if you like

amongst the men, who was supporting you at that time?

interesting thought. Um, we all knew each other as uh 4 married couples"

(Carer 4;114-120).

"Um friends, uhm colleagues (pause) were supportive in that passive way that men are because everybody's horribly embarrassed by other people's illnesses

and uh you don't know what to do because there is nothing you can do it's an individual battle that has to be fought." (Carer 4;133-137).

"But it's knowing that there are other people going through the same sort of thing that we've gone through" (Carer 7a;484-485).

From the superordinate theme of 'support' it was apparent that the men saw little distinction between support and friendship in their relationships with friends and family.

8.5 Developing Understanding of the Findings

The findings from the MaCE study broadly fell into the four categories:

- When being with becomes caring for
- A Sense of Self
- Being separate together
- Connecting friendship with support

However, it became apparent that these categories did not occur independently of each other, or indeed in a linear fashion. There was very little evidence to support a temporal element to the caring experience as all these categories were evident from the onset of the research time frame. Despite returning to the carers on three different occasions with a couple of months in between, their experience was largely unchanged. The carers returned to the same themes for example, stress of caring, sadness at changes in spouse, isolation, and loneliness at each of the three interviews highlighting the need for them to make sense of their

experience for themselves by giving the experience the importance it demanded as they saw it. This process of making sure the accuracy of the events, the sequence of those events and the detail they gave me of their experience, showed a depth and commitment to their experience that was humbling and intensely moving. This depth of experience forms the basis of the discussion.

The findings from this research are both expected and surprising; expected because the experiences of the men interviewed identified known stresses and difficulties with caring for someone twenty-four hours a day, in terms of practical issues and the impact this had on their own health. Some of the findings - self as spouse, valuing the positive, and friendship/support - were surprising because the assumptions that society attributes to caring, paints a picture of it being burdensome, a negative experience and one of dependence that the cared for submit to at times. This was not the findings of MaCE and as such the men highlighted the commitment and ongoing value attributed to their situation. The breadth of the experience of caring for those with cancer and/or dementia was demonstrated in all the quotes as shown. All the carers were open and honest with me in recalling their experiences making the interviews intensely personal and poignant. The carers were keen for others to know what being a carer meant to them and they tried to explain this to me. At times the carers became emotional, recalling the enormity of their role and the realisation of the loss they were to face. All of the carers, however, found moments of positivity and humour within their situation.

The MaCE study findings show a wide ranging experience that defines the men's' role as carer for their wives. A complex array of intertwined practical, emotional,

social, personal, spiritual, ethical, and an intensely intimate array of feelings and needs, were experienced by them all. Their need and altruistic reasons for participating in MaCE were evident during the interviews and the time I spent with them, and as such the processes and discussion that follow are driven by the need to give a voice to that experience. The findings from MaCE did in part concur with the literature review conducted for the background to the study. Some findings were not universally evident in the preceding literature, such as the link between friendship and support, men and marriage. The existing literature was repeated to establish any new research published in the intervening years 2013-2018.

During the MaCE study digital alerts were created, through the databases used for the systematic review, that highlighted any new published research. During this time 2013-2016 there were no new papers identified by this process. Prior to the discussion a repeated systematic review was conducted, using the search terms as before. This was used to clarify any subsequent research in the intervening time since the alerts had lapsed. A search of Medline, and Cinahl using the terms carer experience, cancer, dementia, isolation and loneliness, homebased care and family caregiving 2016-2018, revealed no new literature. An identical search within PsycInfo revealed 9 entries, of which;

- 5 books discussing Aging, Ageing and Health, and Research Methodology.
- 2 studies were excluded, a migrant carer loneliness study in Israel, and a quantitative questionnaire study of depressed female carers.

- 2 papers were included for review; Vargheese et al 2016 Persuasive strategies for encouraging social interaction for older adults, and Badr et al 2017 Depression in individuals with COPD and their informal carers.

The first study included for review was a quantitative study examining the use of persuasion theory to combat loneliness in older adults (Vargheese *et al.*, 2016). Persuasion theory as identified in this study, looks at 8 strategies that could be employed to encourage older adults to engage in social activity and thereby combatting the issue of social isolation that we know to be detrimental to the health of the older population in particular (Tilvis *et al.*, 2012). The strategies identified below may improve the interaction and participation rates in social activity.

- Incentive theory- 'may win a prize'.
- Observe without participating- participating increases without 'being pushed'.
- Fun strategy- activity based on current or previous interests.
- Reassure support role within activity.
- Social proof- activity suitable as demonstrated by others.
- Friends or potential friend's strategy.
- Facilitator friend strategy- known leader reassurance.
- Acquaintance strategy.

It could be argued however, that persuasion as a strategy for increasing levels of engagement in activity for older adults, may already be adopted by those looking after them, creating an over simplification of a behaviour outcome

The second study, Badr (2017) secondary research survey of 89 patient carer couples, suggests that similar factors that predicts depression in patients also predicts depression in carers. This study's findings concur with others, and the higher rates of depression in female carers, the major finding of this study, is known. Having completed this repeated exploration of any new literature pertaining to the research question, the newly published studies do not add any new knowledge to the findings of the original systematic review.

A different literature review was therefore needed to put the findings of MaCE in context with the known research today.

9. Literature Review following findings

The findings of MaCE suggest that whilst there is evidence in the data supporting the sense of loneliness and isolation felt by carers, the driving force behind the research, there are other issues to explore. With the help of the academic librarian at the University of Warwick, further literature reviews were conducted to establish recent and current research that addressed the issues that arose from the data: the husbands did not see themselves as their wives' carers, the gender identity of a carer was female, and that friendship and support were different. From the identified changes in their social relationships the issue of friendship and support was an important finding and possibly a gender issue.

The 3 main areas for the second literature review were, men's experience and understanding of marriage, gendered roles within caring, and how men viewed

friendship. The psychological database PsychInfo was searched for research regarding men and marriage. The search terms men/males, marriage and carers/caregivers, duty and roles and responsibilities were used. This produced many papers. Searching the Social Science and Anthropology database (International Bibliography of Social Sciences IBSS) also provided many papers. However, using the search terms men/males, marriage, duty, roles and responsibilities and MESH headings to combine results, and restricted the findings to the last 10years, reduced the numbers of research papers. Examination of the research revealed that the majority was concerned with gay, transgender and same sex relationships, economic reasons for marriage, the bringing up of children and adolescent men's views of sexuality and identity. Nine papers were included for review as identified in Table 9.1

A separate search for men and friendship found papers on sexuality, adolescent men and childrearing. Five documents were reviewed and were included for discussion. These are itemised in Table 9.2. The other major themes of "self" and relationships were also searched for in the same way, and extensive amounts of research were found that informed the discussion of my findings.

Table 9.1 Men And Marriage

Author, date, country	Study Design	Sample Population	Main Points
(Egdell, 2013) UK	Qualitative Grounded theory.	13 dementia carers 8 female 5 male.	Carer decision making based on social and cultural norms.
(Evans & Lee, 2014) Australia	Qualitative Systematic Review.	19 dementia carer studies.	Transition- relationship, roles and intimacy.

			Loss- partner and marriage.
(Figueiredo <i>et al.</i> , 2016) Portugal	Qualitative Thematic Analysis Semi-structured interviews.	12 male carers of those with pulmonary disease.	Men are dedicated and committed carers. Relational and generation differences between spouses and sons.
(Rollero, 2016) Italy	Qualitative Grounded Theory Semi-structured interviews	24 male carers of wives with MS.	Caregiving-full time job, changes in couple, importance of social support and social life, gender specific issues, fear of the future.
(Clark <i>et al.</i> , 2017) UK	Qualitative IPA Semi-structured interviews.	6 couples one of which has dementia.	Maintaining a bond Change and adjustment Challenge of coping.
(Youell <i>et al.</i> , 2016) UK	Qualitative IPA Semi-structured interviews.	6 carers of those with dementia 1 male carer.	Relational intimacy explored.
(Kramer & Lambert, 1999b) USA	Quantitative Questionnaire/survey	26 carers no info on disease, or gender ratio	Husbands who entered the caregiving role demonstrated significant changes in household responsibilities, social integration, marital

			relationship, and well-being.
(Ribeiro <i>et al.</i> , 2007) Portugal	Quantitative Interviews Content analysis.	53 men no info re caring for whom.	Masculinity maintained by reframing definition of being a man, reinforcing role of husband, retaining power of caregiving relationship.
(Fine & Glendinning, 2005) UK	Expert opinion. Lit. Review	Huge number of papers examined across decades.	Autonomy and independence, are promoted as unproblematic goals. These contrasting perspectives have separated and segregate the worlds of 'carers' from those for whom they 'care'.

Table 9.2. Men and Friendship/Support

Author, date, country	Study Design	Sample population	Main points
(Corden & Hirst, 2011) UK	Qualitative Semi-structured interviews Quantitative survey	756 couples. 19 interviews.	Challenge for service providers to move away from separate relationship 'carer' and 'caregiver'.
(Boylstein & Hayes, 2011) USA	Qualitative Semi-structured interviews dementia carers.	13 men 15 women.	Retaining marital closeness difficult for spousal carers. Carer education and support needed.

(van der Horst & Coffe, 2012) Canada	Quantitative Survey	24,951	3 components to friendship, number of friends, frequency of contact and heterogeneity of friends.
(Blatterer, 2015) Australia	Literature Review Expert Opinion		Friendship allows for relational freedoms and personal growth. BUT Societal norms mean friendships are curtailed.
(Boyer <i>et al.</i> , 2017) UK	Literature Review Expert Opinion		Paper concerned with work/caring balance and maintaining of support.

In essence, this literature review was an exercise in finding the current research that would aid my discussion as opposed to a more systematic review prior to the development of a research proposal.

10. Discussion

This study, MACE, explored the experience of informal male carers. Through the lens of phenomenological analysis and application of a contextual behavioural science approach to the findings, an experience was revealed that was both nuanced and complex. This experience highlighted the issues of marriage, gender, and loneliness.

After listening to the recorded interviews many times and having transcribed them myself as part of the analysis, a strong sense prevailed of wanting to do justice to this complex set of carers' experiences. Having considered the superordinate themes identified and undertaken the post-findings literature review, the complexity and the "emotional investment" of the experience will be considered

in the discussion of the study findings in the context of the contemporary literature. Each superordinate theme will be discussed in turn, informing the main discussion points.

10.1 When 'being with' becomes 'caring for'

'Being married', as experienced by the married men interviewed, was a recurrent theme that emerged from the interviews data analysis. Their thoughts, feelings and beliefs surrounding being married, and the issue of gender within the caring role, forms the basis of this theme, when 'being with' becomes 'caring for'. These particular aspects of the caring role became apparent as the carers struggled to identify themselves as carers. Carer 7 identified new skills needed for the role he now found himself in (page 109). Adapting to this change in role was a challenge for the men yet something they all managed to undertake. However, seeing themselves as carers remained a struggle as the study findings have demonstrated. This process warranted further interpretation and understanding, in keeping with the phenomenological approach of this study.

10.1.1 Marriage

The role and significance of a "traditional marriage"- a monogamous relationship between a heterosexual couple- as experienced by the men interviewed is interesting. Although this definition of marriage has changed over the years, the Concise Oxford English Dictionary (1993) definition, "Marriage is the legal union of a man and a woman in order to live together and often have children", was the closest 'institution' recognised by the men, adding a legality and formality to a relationship between two people.

It is acknowledged that marriage has its origins in a religious union for the purpose of having children and for the social recognition of a union that is permanent until death (Haviland *et al.*, 2011). This broad and somewhat outdated understanding of a “marriage”, with its many cultural and secular nuances, can be seen as an anthropological and sociological norm (Haviland *et al.*, 2011). Despite attempts to recruit a diverse population sample in the design of the study, this sociological norm prevailed in the research participants. The religious marriage ceremony consists of a commitment from both parties to the relationship, “in sickness and in health” and “till death us do part”, and form part of the vows agreed. (Marriage Service Book of Common Prayer 1549).

The men interviewed described a commitment to their wives consistent with their marriage vows and a sense of duty to their wives. A sense of duty and of it “being the right thing to do” was evident as they took on the role of carer. This interpretation is upheld by Egdell (2013) who suggests that social expectation and one’s own morality drives behaviour; in this case a man taking on the role of carer for his wife by the nature of the fact that he is married to her.

The label ‘husband’ is a social construct defined by a past event, in this case the marriage process and legal union of two people. The label ‘carer’ can also be constructed by a past event, such as someone else’s need to be cared for, and is also a legal status. However, in reality, whilst a past event that establishes the ‘carer’ label might be acknowledged as a point in time for a cancer diagnosis, for someone with dementia becoming a carer may be more of a process. Both labels or titles have utility in some contexts, bringing economic power, social status, value and legitimacy but also have downsides in other areas. For example, challenges to access to care and support services, barriers to husbands being

seen as equal to that of a 'carer' in the case of accessing the services required, and doubting their value to society are some of the difficulties assuming a label or title. The carers interviewed highlighted these complexities and thus revealed the difficult nature of socially-constructed identities. It was interesting to note that whilst the men interviewed wanted to be seen as 'husbands', society demands that someone who shows all the behaviour traits of a 'carer' needs to be attached to that label. The social construct of identity may not help those who see themselves with one label, i.e. 'husband', adjust to another socially constructed identity i.e. 'carer'. Both labels are 'useful' and 'unhelpful' at different times. It could be argued that the label 'carer' has more social value than the label 'husband' when used in the context of economic health care policy, political influence on service provision, and of the negative rhetoric surrounding dependence and draining of community resources (Fine & Glendinning, 2005). The label 'carer' becomes an economic factor for policy makers and service providers. The label 'husband' in the examples cited, is omitted from the discourse and discussion of these subjects. This polarisation of roles suggests that they are or can be independent of each other. The findings from this study refute this and thus encourage a wider, holistic approach to the support for carers. It is the existing relationship, between those who are being cared for with those who are caring for them, that is an integral and essential part of the experience for both.

It is suggested by Clarke (2017) that maintaining the bond between spouses through their shared history and a reciprocity of relationship, forms the basis of the caring role between spouses (Clark *et al.*, 2017). Work by Shim (2012)

highlights the difficulties of maintaining the bond between husband and wife in this way when one spouse's cognitive decline, as seen with dementia, means that shared memories are lost; (Shim *et al.*, 2012), a view shared by Prakke (2011). Commitment to a marriage by both husband and wife can also be expressed by resilience, for example in the face of ill-health, by forgiveness at times of stress, by a reciprocal arrangement of caring for each other, and lastly, by seeing the relationship as a partnership for life (Davies, 2011). All these characteristics were present in the husbands interviewed and at no point did any of them suggest caring for their wives was not something they were prepared to do, within their understanding of their marriage commitments and vows.

Returning the love and support that the men received from their wives during their married lives was a reason cited by Evans and Lee (2014) as to why men took on the primary caring role for their wives in times of need (Evans & Lee, 2014). This reciprocity of roles strengthens the continuity of the marriage in the face of ill-health. The process of caring for a loved one can be an extension of that loving relationship and as such seen as a normal part of a marriage between a couple (Egdell, 2013). This was evident from the experiences of Carers 2, 3, 7 and 9 (pages 108-109). For all the men interviewed, taking on the role of personal care was undertaken without complaint. Both caring and intimate relationships, although changed, continued despite the increasing need for care as ill-health prevailed. The continued commitment to and the value placed on their marriage was evident, Section 8.5. These issues of commitment and values are further evidenced when the nature of a sense of self, and spousal relationships during the caring role is examined.

The social and economic identity of husbands is historical: men went out to work and provided financially for their family, whilst the women looked after the home and/or had part-time employment if any. Women were the primary carers of children, and ran the home (Glick, 1995). Maintaining a work/caring balance was important for Carers 2 and 3 with the men being the breadwinner in the family and upholding the financial role they had always taken in their marriages. However, for both carers, it appeared that this balance maintained their sense of self and purpose, as well as giving them time away from the caring role. Providing for their wives financially also serves other value-driven behaviours, such as maintaining a sense of self, or a sense of self-worth. For these carers, the role of husband and the role of carer could not be separated. These themes of 'self' and 'maintaining self' will be explored in greater depth later in this thesis. "Being married" has many facets and social constructions, both private and public.

Some of the historical identities of being a husband persisted for the men interviewed. When they took on the role of home management, the skills they needed were e.g. cooking, cleaning etc. For a few of the carers, these tasks were then outsourced, in particular, domestic cleaning (Carers 4,5, and 9). Providing meals and nourishment for their wives became a full-time job for the carers and finding the time for shopping and cooking added another task to their already busy days (Fjellstrom *et al.*, 2010). For those caring for someone with dementia, the ongoing decline in understanding of the need for eating, and the physical abilities needed to feed themselves, meant that persuading their wives to eat was a source of stress and anxiety. This issue was expertly portrayed by Carer 5 as his wife who had enjoyed going out for meals now [did not](#) enjoy them continually

passing her unwanted food onto her husband who found this extremely embarrassing and frustrating when amongst friends. For those caring for someone with cancer, the side effects of the chemotherapy and radiotherapy treatments meant that meal times often produced distressing emotions and feelings when food was not wanted or increased the pain and discomfort experienced by their wives. This meant that for all the carers, whether they were caring for someone with dementia or cancer, providing food led to increased anxiety and took away the enjoyment of a meal together or with family and friends. The more personal aspects of caring for their wives, for example, washing and dressing, were undertaken by all the men without complaint. As a group they all had very close and caring relationships with their wives and this “caring role” was seen as an extension of them being married.

During the interviews, the men highlighted the differences between themselves and their wives and the roles they had within their marriages (Section 8.5). Running the home, providing meals, and caring for children and parents, were seen as their wife’s domain. Now that they were needed to care for their wives in ill-health, they felt unprepared and ill equipped to do so.

10.1.2 Gender

The question of gender became apparent during the interviews with the men in this study. They openly identified differences in how they and their wives coped with ill health (Carer 2 Section 8.6), how their gender roles within their marriages had changed (Carer 4, 5, 9 Section 8.6.1) and how they themselves explained and understood their changed situation.

With the rise in the numbers of informal or family carers needed by society, and more specifically a rise in men being carers, this disparity of understanding and knowledge of their experience needs to be addressed (Del Bono *et al.*, 2009). It is suggested that gender identity has a part to play in how men adapt to their new found caring role, and how they make sense of it. A move to a more performative view of gender, as opposed to the historical theories of fixed gender roles, have highlighted the social context in which individuals operate (Seale & Charteris-Black, 2008). Coates (2004), suggests that men like to discuss impersonal topics such as sport, thereby co -creating male solidarity or “homosocial desire” with other men; maintaining masculinity in social contexts (Coates, 2004). The adoption of a caring role traditionally seen as women’s work (Calasanti & Bowen, 2006), erodes this sense of masculinity both privately in their relationship with their wife, and also publically in their social interactions with others (Ribeiro *et al.*, 2007). Importantly, findings of MaCE challenge this masculine identity, or certainly the assumption that men focus on impersonal topics, and the men themselves were very open, honest and intimate in the way they approached the interviews. This commitment to talk about sensitive issues around caring for their wives contradicts the assumptions of Coates (2004). Three of the carers (Carer 4,5 and 9) highlighted at the end of the time span for the study that talking had been a considerable help to them. As the focus of the interviews had remained steadfastly on their experiences of caring, it appears that this was not unduly challenging or uncomfortable and that given the opportunity to discuss their role they were happy and keen to do so. Today’s society requires endless admissions of “self -revelation and vulnerability” in the media and the public consciousness. These characteristics are more usually associated with the exchanges between

women (Seale & Charteris-Black, 2008). It could be argued that when men are asked to engage in this form of dialogue and expression of experiences, they find it harder to voice their experiences in the language expected of them. Given this gendered approach to men's experiences of caring for their wives, their responses are couched in scientific and factual accounts. Typical scenarios and language seen to explain their experiences were ones of "facing a battle" against the diagnosis or illness to maintain their sense of masculinity at this time (Rollero, 2016; Figueiredo *et al.*, 2016).

As men change from an active part in a working society to a more private role in retirement, their role and responsibilities change as they are called upon to care for their wives (Russell, 2001; Russell, 2016). It is suggested that "men approach the caring role as a combination of management and nurturing" p42 (Sanders & Power, 2009). All the carers in the study outsourced some of their new responsibilities as they adapted to their caring roles for example gardening, cleaning. However, they took their role in personal care for their wives very seriously and compassionately reluctantly using professionals for personal care. Managing their day to day lives was helped by the delegation and time management skills they had used during their working lives. As well as using problem solving skills, traditionally associated with their working life however, new skills are needed to cope with the day to day caring role.

New skills highlighted by Fjellstrom *et al.*, (2010) that are needed by some men suggest that day to day worries about providing care for their wives was a concern. Although some of the men interviewed felt adequately prepared for cooking, those who had not done it previously in their married relationship saw it

as crucial in their new role. For the two carers who had very few cooking skills, they identified learning as they went along. Carer 5 (p 92) did not like cooking; and having to complete this daily was a source of stress. In addition, his wife ate very little and he found it very difficult to persuade her to eat anything.

Men and women use health care services very differently (Wenger, 2011); men go to the doctor less often than women (Robinson *et al.*, 2014), ask fewer questions once at the doctors, and generally underplay their symptoms and problems. In MaCE, the men interviewed described several examples of delaying their own health care needs in preference to caring for their wives (Carers' 5 and 6 Section 12.4.5). This could have an impact on their abilities to continue to care for their wives in both the short and longer term. Identifying this behaviour, the underplaying of symptoms and problems, known to be a facet of 'male' help seeking behaviour, could help us to understand one of the barriers to accepting help by male carers. Continuing to use these traits, beliefs, and behaviours whilst caring for their wives may prevent access to support for them and their wives. In contrast a study by Gast and Peak (2010), suggests that men do seek help in the pursuit of being a good provider for themselves but often need their 'wives to broker the deal' (Gast & Peak, 2010). In the case of caring for someone with dementia, this encouragement to seek help either medically or for practical support may be lost. The primary reason for men seeking help is to rectify physical symptoms (Moller-Leimkuhler, 2001). For those with dementia, if the 'symptoms', as understood by their carers/husbands, are not deemed to be 'symptoms' by the nature of the fact that they are not physical, then help is unlikely to be accessed. Non-perception of symptoms, a reluctance to ask questions,

under-playing of any problems and normalising of these symptoms leads to a delay in help-seeking behaviour by men in the caring role. Whilst these studies examined the use of help-seeking behaviour for men themselves, it would be reasonable to extrapolate that they would apply these ideas and beliefs to those they are caring for, in the absence of any other strategy.

Decision-making in men to accept help has been firmly placed in the social construction of what it is to be male. Help seeking is seen as female behavior and as such is not associated with or by men (Noone & Stephens, 2008). As has been highlighted above (page 155), the language men use to discuss topics can be different from the language used by women. Whilst maintaining their masculinity, there is the potential for external confusion to arise when these nuances of communication are overlooked. Gender socialisation as theorised by Mansfield *et al.*, (2003); O'Brien *et al.*, (2005); and Tannenbaum & Frank (2011) suggests that how men think of themselves, and how society demands that they behave further complicates the decision-making process when accessing help for those they care for. It could be argued that the need for independence, self-reliance, and a denial of pain and illness are socially embedded in the roles of men (Gast & Peak, 2010). Suggestions that this traditional masculine identity hampers how men make sense of their need for help is upheld by the findings of MaCE. The men in MaCE are no different, as evidenced in section 8.3, and are influenced and constrained by the roles and responsibilities assigned to men.

Having looked at a sociological model of what it is to be male, the issue of decision-making overlaps an additional discipline - that of social psychology. Social psychology suggests that there are defined processes at play which make sense of help-seeking behaviour;

- Normativeness; whether, in this case, the man sees his experience as normal or common.
- Ego centrality; does this experience mean there's something wrong with me? Have I caused the problem in some way?
- Conformity; does my experience conform to others experience?
- Reactance; will I be able to retain my control of the situation? Again, the carers interviewed evidenced their feelings of loss of control (Carer 4 12.4.6).
- Reciprocity; she would do the same for me or has done the same for me/family (Mansfield *et al.*, 2003).

This internal, individual approach to a sense of self highlights what it is to be male. Socially constructed ideals of what it is to be male, added to internal concepts and beliefs of this, contributes/ leads to a complex layering of experience of, in this case, what it is to be a male carer. All of the processes identified above have been evidenced by the carers interviewed (see quotes Section 8.5) and give added complexity to their decision-making at times.

The final element of gender, highlighted here in the discussion, is the role emotion has to play in the decision-making process for these carers. As healthcare services have been reformed, the reliance on family carers has increased (Baxter & Glendinning, 2013). This reliance on informal carers in turn gives the carer increased responsibility. This responsibility increases their emotional investment in the decisions they are having to make and was evidenced by Carer 7b who was asked by a doctor to decide whether the consultant psychiatrist needed to

see his wife again. This was both confusing and frightening for him (page 97) as he felt ill-prepared to make that decision. Theories of emotional coping suggest that negative emotions prevent people from making decisions (Baxter & Glendinning, 2013). If the person making the decision fears the outcome of the decision they are about to make, then they often delay coming to a decision. It has also been shown that, in general, people prefer the status quo or the certainty of their current situation and are reluctant to make decisions that change this. An example of this may be the need for respite care for the person with dementia. This decision may be delayed for the fear of the outcome of the decision, for example once the person concerned has gone into respite care, a short term placing, there is the fear that this may become permanent. This reluctance to upset the status quo can continue until the point that a crisis occurs. This highlights the need/desire to maintain the current situation by the carer to prevent potential unwanted feelings of loss when the person they are caring for is placed in respite care (Ho, 2008). Such a delay may be detrimental to the person with dementia if their care and well-being suffers. This delay in decision making around respite care was illustrated by Carer 5b (pg 97).

The major themes of marriage and gender were accompanied by several smaller themes, as shown in the findings (Section 8.4.1), that also warrant exploration. All the men gave examples of their multiple caring roles and how these additional roles impacted on them caring for their wives. Grandparents looking after grandchildren, sons looking after fathers, and carers looking after friends and family indirectly as their caring role continued. The caring boundaries within society and families has changed over the years (McNeil & Hunter, 2014). As identified within the role of marriage, these roles and responsibilities have been

affected by change. Economic changes have meant that those who have not worked, for example women, now have to, meaning their traditional role of childrearing is done by others, for example grandparents (Boyer *et al.*, 2017). The need for women to work outside the home has seen rapid change since the 1980s (Avdela, 1999), challenging masculine assumptions and role stereotypes. By 2000, the dual earning family is the norm in the USA and therefore families were relying on grandparents to help with childrearing and care (Barnett & Hyde, 2001). This change in the structure of families, from the nuclear family of two heterosexual parents with two children, to a more inclusive family of wider relationships is becoming evident in today's society (Bengtson, 2001). It is argued by Bengtson (2001) that a broader idea of the family is needed as a wider inclusion of diverse relationships are added to the family structure. Those who move geographically to find work are not able to rely on family for child rearing. For some of the carers in the MaCE study, juggling this role in addition to caring for their wives led to tension. The increasing longevity of our parents in an age of advancing healthcare, reduction in poverty, and improvements in nutrition and housing, has meant that as 'children' we may be called on to look after our parents (Gomes & Higginson, 2008; McPherson, 2015; O'Sullivan, 2015).

The complexity of the caring role that the men undertook for their wives was widely recalled during their interviews. With the investment in more complex and wide-ranging treatments for cancer in particular, the medication management that fell to the informal carers caring for them is both complicated and a responsibility that some are not be prepared for (Oberg, 2004). The regimes of medication and treatments, as described by MaCE Section 8.4.3, provided a disparity between

the severity of the disease and the reality of the care needed by their wives e.g. Carer 2. This disparity may be conceptually difficult for carers. Advanced cancer, by its definition as a recurrent disease or disease not responding to treatment, is a frightening and heartbreaking situation for patients, family and friends. The criterion of advanced disease, as required for inclusion in MaCE, identified scenarios where the diagnosis and care needed did not match, especially for Carer 2, Carer 4, and Carer 8. On paper, their wives were extremely ill, but in practice however, they needed little or no 'care' as understood by the men. This disparity led the carers to feel confused that they were included in a study of carers, when they didn't feel like a carer or identify with this label. This identity crisis has been explored from the issue of marriage and gender in the thesis, however, supporting the carers/husbands at this time of uncertainty and disbelief in some cases is needed. Education and information from professionals may be the support they need at this time (Grande *et al.*, 2009), which will be explored later in the thesis.

Having looked at the themes of marriage and gender within the caring role from a social constructivist point of view, it may be helpful to take another stance when looking at the 'self'. A contextual behaviourist approach examines behaviour within the context of the experience, and this allows understanding and interpretation of the male carer experience. It is not sufficient to know what an experience is; a pragmatic approach is needed to examine the experience and thereby increase understanding of that experience. Examining behaviour in context allows a greater understanding of an experience by moving away from labels and titles, or socially constructed identities, that may hamper ones

understanding of that experience. By using an approach to understand the lived experiences of others that is unbiased, and that challenges beliefs and assumptions, one can broaden one's understanding of the lived experience of others and also widen the approaches for care and support that may become available.

10.2 A 'Sense of self'

A sense of self can be described as how we think of ourselves in any given experience or interaction with others; it is influenced by our past history, beliefs, thoughts, feelings and emotions. All these factors can be used to predict and influence our behaviour in the present. All the men interviewed in MaCE gave examples of how they saw themselves before and during their experiences of caring for someone with cancer and/or dementia Carer's 5, 6 and 9 (Section 8.5).

Mankind has been fascinated by the human mind for centuries - philosophers, clerics, psychologists and medics alike. Descartes (1596-1650), "I think therefore I am" is often championed as one of the first philosophers to identify the human mind as an entity. Before that the body was thought to be controlled by the major organs, the heart and liver. The study of human behaviour developed from the study of animal behaviour; however, Skinner's departure into Radical Behaviourism allowed the human mind (the radical part), and therefore cognition, to be included in his approach (Skinner, 1987). There have been many theoretical models aiming to explain the sense of self, Berne (1910-1970). Transactional Analysis describes the ego, the central 'real self', as something that operates in three different personality states. These states, the Parent, Adult, and Child are

separate from the 'real self' and both influence and affect our behaviour at any given time, or when faced with any given experience. These were developed, by Berne, from Freud's thinking and his preoccupation with the study of the subconscious (Berne, 1964). Jung's (1875-1961) 'Theory of the Self' was based on the premise that the unconscious and the conscious parts of the mind were combined to form 'the true self' (Stevens, 1994). The 'self', as identified by Western approaches to psychology, focuses on the individual and a sense of independence from the body. This has been openly challenged in recent times by Sampson (1989) and Rose (1998) who suggest that this focus on the self, promotes and explains the idea of power in society (Rose, 1998). Foucault's (1926-1984) theory of the self identifies the relationship between power and knowledge and as such places the concept of the self in a socially constructed framework between these two entities. He believes that the self is influenced through education, media and society, and this is the power that is everywhere as the source of discipline and conformity.

The Eastern tradition of Buddhism uses a variety of traditions, beliefs and practices to make sense of our experience in the world. This spiritual approach to our sense of self and the suffering of the world suggests that holding on rigidly to a particular sense of self, for example, I am a husband, or I am a carer, affects one's behaviour at all times and leads to suffering (De Silva, 1990). The idea that the world is constantly changing, central to Buddhist teaching, includes us as individuals in that world. Developing psychological flexibility, the ability to change and adapt to new experiences and situations, by the way we make sense of our

experiences through examination of behaviour, increases our abilities to adapt and change to those experiences.

One contemporary model of the self, which could be of use in making sense of the participant's experience of a changing sense of self, is offered within Contextual Behavioural Science (CBS). This model is the science of human behaviour relating to and embedded in events that make up our experiences and our understanding of them (Vilardaga *et al.*, 2009). CBS was chosen, as one contemporary model, to explain the behaviour demonstrated by the findings of MaCE, and for its evidence-based approach. The strength of this approach, it can be argued, is that it is not enough to know and understand behaviour but to then have developed clinical strategies to help with this understanding, and as such CBS can be seen as a scientific pragmatic model for the understanding of human behaviour. The development of clinical and therapeutic approaches, such as Acceptance and Commitment Therapy (ACT) and the use of Mindfulness, give rise to services that may help and support those providing care. These clinical and therapeutic approaches will be discussed in Chapter 17. An extension of Skinner's Radical Behaviourism, CBS, sees all human behaviour as being shaped by the context in which it takes place, and especially the functional consequences of the behaviour. Unlike early forms of behaviourism, which originated in the study of animals, CBS sees the internal experiences of humans, such as thoughts and emotions, as relevant aspects of context and behaviour. This internal cognitive understanding or awareness of human behaviour is scientifically analysed in a CBS approach. What differentiates human behaviour from animal behaviour is our ability to predict and influence future behaviour. CBS

allows our behaviour to be understood with 'precision, scope, and depth' p12 (Hayes *et al.*, 2012) and is a process that has advanced and developed from the early behavioural science (Skinner, 1987). Such advanced analysis allows us to understand the most complex of human behaviour, including the individual and personal response to a set of events or experience, in this case caring for someone with cancer and /or dementia.

A central element to the CBS model is its view of the concept of Self (McHugh & Stewart, 2012), which has clear relevance to the experiences reported by the participants of MaCE. The three components of 'the self', as highlighted below in the discussion section, are evidenced from the findings of MaCE and add to the understanding of the lived experience of the informal male carer.

It is posited that the self can be viewed as having three component processes:

- Self as content.

This part of us is learned. It is all our thoughts, feelings, stories we have told ourselves, and the rules we have assimilated over time, as we have experienced the world around us. We constantly change and adapt our sense of 'self as content' to fit social purposes and situations. It is this aspect of self, the 'self as content', which is most easily accessed, and may represent what many people would think of as the entirety of the self.

- Observing self.

This self-awareness is a process (rather than a set of content) which allows us to observe our thoughts, feelings, experiences, stories etc. ('self as content'), as

well as being able to turn our awareness to things in our external context (e.g. Environment, other people). Developing this 'observing self' is held to be an important part of noticing and being able to act differently upon our thoughts and emotions.

- Self as context.

This refers to the idea of the Self being more than the 'self as content', thoughts, feelings and memories etc. and more than the 'observing self' as a process. This construct refers to the self as being the context which contains both the 'self as concept' and the 'observing self'; it is the place where experiences occur and are noticed. As such, it is more continuous than either the changing set of experiences which are 'self as content' or the fluctuating 'observing self' (Hayes *et al.*, 2012); taking this perspective is held to allow us greater distance from our thoughts and feelings and therefore more able to make wise choices about our behavioural responses to them. This is in contrast with acting as if on 'autopilot', based upon existing conditioning and learned rules which is held to deny ourselves the possibility of choosing another type of response that is more in keeping with our values, leading to a more satisfying way to live our lives. Thus 'self as context' 'refers to the ability to step back and take a flexible perspective on what you think, feel, perceive and do' p137 (McHugh & Stewart, 2012).

CBS provides a specific account of the processes underlying this perspective-taking. This approach is Relational Frame theory. This theory is based on language and how we convey our experiences, thoughts, feelings and understanding of these entities to others (McHugh, 2015). The ability of humans

to do this depends upon the development of the ability to perceive three basic distinctions:

- The difference between I and YOU.
- The difference between HERE and THERE.
- The difference between NOW and THEN.

These distinctions (referred to as 'deictic framing') create an interpersonal perspective (I/YOU), a geographic perspective (HERE/THERE) and a temporal perspective (NOW/THEN). This demonstrates a tangible knowledge of the self, verbalized in language and interactions with others (McHugh & Stewart, 2012).

Looking at our sense of self and our behaviour from a contextual behaviourist approach, the idiographic nature of the experience is examined through individual behaviour in detail and in a precise way (Hayes *et al.*, 2012). This approach differs from the social constructivist approach of looking at an experience from a general, nomothetic stance. By using a contextual behaviourist approach to the findings during the analysis and the development of the themes at all stages, the idiographic focus and interpretation of the data are consistent with the phenomenological approach of the study. Using IPA has elicited the male carer experiences of caring for someone with cancer and/or dementia, using the specific technologies employed for data analysis as outlined in Chapter 8. One way of making sense of these findings is by using CBS in the context of being a carer caring for those with cancer and/or dementia.

The themes that were generated from the interpretation of the men's interviews were as follows;

- Changing self.
- Maintaining self.
- Self as spouse.

10.2.1 Changing Self.

The lives of the men interviewed have changed considerably since their wives had been diagnosed with cancer or dementia. For some it has meant learning new skills, learning to cook, clean etc. as they took on roles and responsibilities they had not needed to until now. It could be argued that as the men considered taking on these new skills their sense of 'self as content' may have been challenged in their new role. This process of adapting to a new 'sense of self' satisfies the new role they were now undertaking. In a practical sense, they are also now equipped with the skills to carry out their new tasks.

For Carers' 4,5, and 6 Section 8.5.1), they themselves were changed by the caring role they now took on. Additional skills specifically akin to caring had to be adopted, for example administering medication, monitoring symptoms, attending appointments for treatment etc. This change can be understood more fully by looking at the 'self in context'. How one understands themselves NOW in contrast to how they understood themselves THEN. This temporal element adds a depth to the experience of the men interviewed. This relational frame is an example of perspective-taking in one's life experiences and helps us to change behaviour or

persist in behaviour depending on which leads to a more fulfilling, values-driven life.

Carer 9's self-awareness or the 'observing self' can be evidenced by his words about changes in their lifestyle (p 117). His awareness of the need to change his behaviour to suit the needs of his wife as her dementia worsened meant that he had to 'slow down, and not 'rush things' as she found that very difficult to cope with. As we can see from the quote, he was aware of this and as such shows his 'observing self' in action. This carer's awareness is important because it improves the quality of life for them both and helps to understand the changes needed in his experience of caring for someone with dementia.

For Carer 2 (pg 128) however, this self-awareness of how he approached the uncertainty of his wife's cancer progression and remission, logically and pragmatically, meant that he could carry on as the need to modify this particular behaviour was not needed. She was able to understand his need for logic and pragmatism as he had applied this to events historically during their marriage. This different acceptance to change, by the men in the study, was pertinent between those caring for someone with dementia and for someone with cancer as there was no cognitive deficit for those women with cancer. In the presence of cognitive decline, as seen in those with dementia, change is needed in the 'observing self' in those caring for them.

When adapting to the caring role, 'self as content', all those thoughts feelings and emotions learnt by our experiences of previous caring, observing others caring etc. is changed. As we can see by Carer 7's experience (page 117) of adapting

to his changing role, his thoughts of what a carer does influences his understanding of what he is doing for his wife now.

Perhaps a greater awareness of our 'self as context' means that we are less fused with particular elements of our 'self as content', our stories, rules etc. which enables us to be more flexible in making sense of the experience and the demands of caring for those with dementia. For Carer 2, who was caring for someone with cancer, with no or very little cognitive decline, he demonstrated a less dramatic change in 'self as context'. The psychological flexibility gained by an awareness of the sense of the 'observing self', allows for different responses to be chosen more in keeping with one's values, as the cognition and needs of those being cared for deteriorates. Therefore, undertaking care for another challenges our thoughts and feelings, and changes our behaviour in the context of this new or different role. There is no part of us that is not changed in the act of caring for another. However, our values and beliefs continually drive one's behaviour, even if the context in which this behaviour has changed. By using a CBS analysis, it is apparent that our values stay intact, and therefore help maintain our sense of self.

10.2.2 Maintaining self.

The men interviewed described knowing that they needed to maintain their own 'sense of self' if they were to continue to care for their wives for any length of time. As earlier work on caring for someone with dementia has shown (Murray *et al.*, 2005b), the caring trajectory can be 7-12 years in some instances. Maintaining interests and hobbies was described by all the men as very important

(8.5.2). They needed their friends and family to help them maintain activities, and in so doing serve these values and behaviours that reinforce their 'sense of self'. They openly acknowledged the importance of this (p 108). Salient to note, however, was that over time the importance placed on the needs of their wives overtook their own needs and 'sense of self', and as such most of their interests and hobbies stopped or were reduced. This included attending meetings (Carer 6, p77), or trips to the pub with friends (Carer 5, p77). The desire to care for their wives, protect their wives in the face of a lack of interest and prejudice from others, and maintain her 'sense of self' was something they took on in the face of cognitive decline and physical infirmity. Maintaining a 'sense of self' for their wives was captured very powerfully in the experiences of the men interviewed and came across in the transcripts repeatedly. This factor was more prevalent, and articulated more frequently, than the assumption that the carers faced of a loss of self within their caring role (McLean *et al.*, 2016).

Carer 7's account of day to day living with his wife and her dementia meant that he was only able to do the things he needed to do, that is pay bills, plan talks, and relax, when she had gone to bed. They both led very full and busy lives talking to groups about living with dementia; however, his accounts of spending hours on the computer doing day to day administration late at night explains how he adapted his day to fit in with his wife's needs. As we can see from his quote (p 101), this carer's prioritising of his wife's needs, for example, needing help to get to bed, and getting the bills paid, come ahead of his own needs to relax and rest. This time-consuming array of needs that need to be met, highlights the breadth and depth of the carers' experience. The evidence from Carer 7 can be

seen as an example of his attempts to maintain his 'sense of self', in this instance maintain his sense of what it is to be a good husband. This example of ensuring the bills are paid and therefore maintaining the electricity supply or gas supply is congruent with his role as spouse and the values attributed to it – "Provider, caring for M".

10.2.3 Self as spouse.

Seven of the 9 carers were married to those they cared for and for all of these couples it was their first and only marriage. Carer 1 was a son-in-law, and Carer 6 had been married once before. As we have discussed before (Section 8.5.3) all the men had undergone changes in their roles as husbands as the need for caring for their wives had continued.

An example of this change can be seen in the experiences of Carers 2, 5 and 7 where they had become the sole administer of medication, monitoring of medication side effects and symptoms, and transporting their wives to hospital. This was a change in how they experienced their 'sense of self' in context. In the past, caring for their wives may have involved earning an income and doing the gardening. These are behaviours associated with 'being a good husband'. Monitoring and administering medication had now become framed with caring and therefore was also part of 'being a good husband'. Once this new behaviour has been assimilated into the 'sense of self' of 'being a good husband', the two very different behaviours can be viewed as the same 'functional class' of behaviour and therefore the same. This way of looking at elements of behaviour increases understanding of being a carer and being a husband, and may be helpful when making sense of experiences.

This example of breaking down behaviour into elements is one way of making sense of the way in which the men interviewed found identifying themselves as husband or carer problematic, when in fact their behaviour seen in this way explains how both titles or roles may be congruent. By looking at their behaviour in context, we can see how this value of 'being a good husband' can be served by different behaviours. All the men interviewed identified very little difference in how they saw themselves in the context of their marriage and in the context of being a carer; they saw both their roles as one and the same. This was important to note and, as such, may explain how these blurred boundaries may play a part in how the men interviewed expressed and made sense of their caring role and how they identify themselves as a carer or not.

For Carer 5, maintaining his wife's weekly trips to the hairdresser was very important as well as organising appointments with the beautician in the absence of his wife's ability or understanding to do this. Adopting this new behaviour of organisation of her needs was now framed with caring within his self as spouse. He was very uncomfortable with this and this was expressed by his admission that "he was doing things he never thought he'd have to" (p 92). His anger and frustration with this new role, was evident in his interviews and was directed at his wife in this instance. Perhaps holding rigidly onto previous rules or beliefs about 'being a husband' or 'being a wife', 'self as content', is hampering this carer's ability to understand his new role, and therefore making sense of it. For Carer 5, this was difficult as seen by other examples of anger and frustration, tears and disappointments over the lack of support from his grandchildren (p 124) recalled in his interviews.

Carer 8 found the disparity between being a carer and a husband difficult to understand as he could identify the importance of both labels and was not sure which one to align himself with. Framing roles and behaviour as inherently female or male descriptions of how we see ourselves, however, can be unhelpful if they are held onto tightly, prohibiting alternatives to be seen. An example of this would be the husband who believes that the behaviour he associates with being a carer is female, (Carer 7 p 92), consisting of nursing duties, with thoughts on dependence and disability that may be strongly reinforced within his own conceptualised 'sense of self'. Within CBS, this would be constructed as the concepts of 'Carer' being associated with 'Female', and in opposition to 'Male'. Whereas, someone who saw 'carer' as a component of 'husband' may react differently as in the case of Carer 3.

The benefit of looking at the men's reported experiences through the lens of CBS is arguably this; that many of the details of their day to day experience, their emotional reactions, the specific thoughts that occupy their minds may have changed from before their wife's illness. They may feel that they are a 'different person' in some ways, from the experiences they recalled for example, cooking, cleaning, and administering medication. However, this model can accommodate these perceptions as various and important pieces of 'self as content', while other aspects of their 'self as content' for example 'I am a husband' or 'I am a protector' are continuous. The ability to observe and notice these perceptions may be helpful when making sense of an experience, in this case, self as spouse, allowing one to be less likely to automatically follow stories and rules which are now less helpful.

Having considered the processes involved in the changes from 'being with' to 'caring for' the individual and the changes in the sense of self as content, the 'observing self,' and the 'self as context', an examination of these changes from 'outside' the individual will be considered.

10.2.4 Transitions

During our lives we all experience change and transitions. These changes may result in new relationships, new behaviours and as we have seen, a new 'self as content' (Schlossberg, 1981). If these parameters are used to categorise the changes for the men in this study, then we could logically assume they had experienced or passed through a transition in their lives. Applying this to the husbands interviewed, they had become carers. However, when analysing and considering the interviews, if the husbands were identified as carers by others then when did they become a carer? A distinct role as a 'carer' is something that one transitions into at a given time-point (O'Connor, 2007). If this is the case, and the men in this study refute this, when did it occur? Transitions are changes we all go through throughout our lives (George, 1993). Some of these developmental changes are expected, for example the move from child to adolescent to adult, whilst some are unexpected, for example becoming the carer for your spouse. How these transitions are managed leads to a sense of well-being in our lives. In the past, transitions have been seen as occurring after a particular life event, and the need to see them as ongoing life processes provides us with a more complex understanding of life experiences. The move to 'carer' can be seen as an example of this linear approach to life transitions. Kramer and Lambert (1999) suggest that the move into a caregiving role is more of an extension of an existing role, in this

case being a husband, than a traditional change of role into another role (Kramer & Lambert, 1999a). This approach is seen and upheld in the experiences of the carers interviewed. All the men in MaCE described caring for their wives as something that they had always done within their marriages and therefore agree with the work of Kramer and Lambert (1999). The fact that they now had different tasks and ways to achieve this, was perhaps not the transition to being a carer but an extension of their role as husband.

Transitions associated with ill health are much more subtle, and more complex than a 'one-time' move from well-being to ill health (Reinke *et al.*, 2008). It could also be argued that throughout the prolonged decline of dementia for example, there will be many transitions as the needs of those being cared for changes, the disease changes and the needs of those caring for them change. There are suggestions that transitions in the relationship between spouses coincides with changes in the spouse with dementia (Evans & Lee, 2014). The men interviewed highlighted changes in their relationships as the disease changed the cognition and physical abilities of their wives, and from the quotes given found this ongoing change relentless and constant.

If caring for their wives is an extension of their role as husband as the results of MaCE suggest, and all of them preferred to be known as a husband, the title or role of carer needs to be examined. Suggestions that the term carer does not explain or give sufficient value to the relationship between those being cared for and those caring for them has been highlighted (Molyneaux *et al.*, 2010; Henderson, 2001). Agreements that the term carer suggests that one has stopped being a husband to become a carer has also informed this debate. This

move suggests a distancing or change in relationship with those that are being cared for. The values and responsibilities attributed to the role of husband are somehow no longer applicable, and the role of carer supersedes that of a husband in the minds and opinions of others. Molyneaux (2010) also suggests that a 'carer' is an economic resource, more suited to the needs of statutory services and policy makers, rather than that of being a husband. An additional argument suggests that the term carer has negative implications regarding the dependence of one person on another, and also that those cared for are a burden on their carers (Ribeiro *et al.*, 2007). The idea that a more inclusive term should be used to acknowledge the partnership and mutual support that occurs in relationships, without using terms that differentiate and divide the relationship into separate and disparate parties is an alternative view (Molyneaux *et al.*, 2010). From a contextualist perspective, there is not a 'thing' which is a carer. This is a term or label which people might usefully use in some contexts rather than others: e.g. useful for care planners in doing a needs assessment, not so useful for husbands describing their self-identity.

It is noteworthy that since the publication of Kramer and Lambert (1999), research has shown that husbands adopt many changes when faced with caring for their wives in ill-health that they had not been exposed to before in many cases. These changes, for example completing household tasks, personal care of their wives, and a contraction in their own social interactions with others, has maintained the idea of 'a carer' as an entity in itself. The polarising of the experiences between carers and those they care for, however, has not greatly enhanced our understanding of the caring experience (Kramer & Lambert, 1999b). Research

has often been divided into carer and patient studies. It is only since 2010 that this separation has been challenged (Molyneaux *et al.*, 2010; Evans & Lee, 2014). The earlier ideas and beliefs as to what constitutes a 'carer', that framed carer research, had identified an experience seen from the outside (behaviour), without connecting it to the context in which this behaviour occurs. Therefore, a contextual behavioural approach adds a different dimension of behaviour seen in context to this discussion.

Whilst the idea of a formal transition from the role of 'husband' to 'carer' for the men in the MaCE study was evident from a social context in the way others saw them, how they managed this privately or how they made sense of it for themselves will be discussed at length in the following section.

10.3 “Being separate together”

The findings for 'being separate together' highlight the changes that the carers experienced in their personal relationships. The changes in their relationships with their spouses and immediate family were highlighted in the findings of MaCE (Section 8.6). The men interviewed needed to become advocates for their wives as their cognition declined. The positive aspects of their caring role as it was now, built up a picture of complexity and emotional change. Examining the themes of advocacy and valuing the positive highlighted the importance of connection and togetherness in a relationship that was continually changed by ongoing disease, and how the breakdown of these processes led to feelings of loneliness and isolation.

As already highlighted, the socially constructed roles and responsibilities of a couple, both privately and publicly, are affected by the physical and cognitive decline of the person with dementia, with the cognitive decline being the most difficult to observe for the husbands. Whilst the evidence from those caring for those with dementia was compelling and heartbreaking, this differed for those whose spouse had cancer and as such the physical decline was what changed their relationship the most (Carer 4, p 113). The results of MaCE highlighted that the husbands of those with dementia went to great lengths to preserve their relationships with their wives, even though it was emotionally very difficult for them. They showed examples of couplehood (Molyneaux *et al.*, 2012), a sense of togetherness, and connection with their wives that was both touching and caring (Carer 3, p 116). A much greater sense of nurturing and caring was evident from the men than some commentators have argued (Sanders & Power, 2009).

10.3.1 Couplehood

Being a couple cannot happen alone; both parties have a relationship with the other. It is clearly evident that someone with dementia is not experiencing the disease alone, and as such changes in the relationships of those caring for them are inevitable (Robinson *et al.*, 2005). This work by Robinson (2005) suggests that couples use ongoing strategies together to manage the acceptance of the diagnosis, the constant decline of cognition and physical capabilities, and the social context of their ill health. Normalising difficulties prior to the diagnosis, minimising their difficulties on a day to day basis, maintaining separate identities as well as couple identities, and seeking family support are some of the ways in which couples cope. Maintaining a bond with your wife is essential for a caring

relationship to endure during the challenges of ill health (Clark *et al.*, 2017). This marital bond continued to be experienced by the men in the study, and as such was a very important part of their role.

Other research suggests that this sense of being a couple is described as marital closeness (Boylstein & Hayes, 2011). There appears to be no distinction between the two concepts of couplehood and marital closeness, and the terminology is used interchangeably for the same experience. They highlight the disruption of this closeness due to the diagnosis and disease expectations, whilst also evidencing the reconstruction of this closeness through love, commitment and the acceptance of the current situation. The results from MaCE concur with a disruption in the marital relationship. Carer 7, through inclusive language and caring behaviour towards his wife, demonstrates the ongoing closeness and commitment to her through advocacy, caring, and love as her dementia worsens.

Marital closeness or couplehood is often described as occurring as an iterative process rather than a linear one during a relationship (Hellström *et al.*, 2016). This temporality during relationships identifies growth and change and adds further complexity to the carers' experience. Coping strategies for stress and adversity that worked once to maintain a relationship between the cared for and the carer, may need to change during the stress and adversity of ill-health and disease. The presence of ill health highlights the need for constant change in the marital relationship that we see in the recorded experiences of those interviewed. To cope with the change in the relationship, most of the couples described trying to maintain the abilities of those with dementia by subtle prompts during

conversations, in social contexts, and day to day living (Merrick *et al.*, 2016). This behaviour seen in the men interviewed serves two values; firstly, maintaining the person who has the disease, and secondly, of maintaining the love and commitment to that person through marriage. The temporal nature of the experience of couplehood for the men in the MaCE study was not clearly explained by them. They described a sense of couplehood with their wives prior to the diagnosis of cancer and/or dementia, in this case marriage vows, duty, responsibility, and bringing up of children. However, the sentiments they echoed suggest that despite the longevity of the caring role they had undertaken, the continued couplehood with their wives was maintained, albeit differently. At no point did any of them identify an exact moment of diagnosis, and the changes they did see were subtle over time. It was poignant to note that the point of diagnosis from professionals was an exact date, but that the men themselves could highlight difficulties before then that they attributed to the dementia and /or the cancer. This again highlights the importance of the male experience, being understood and heard if increases in our knowledge and ways of providing support are to be informed and credible.

For some of the men interviewed, the explicit understanding of their experience was hard for them to put into words, and based on what we know about the use of gendered language and that men find expressing thoughts and feelings difficult (Coates, 2004), this is not surprising. From the careful analysis of the language used in the interviews, we begin to see that this sense of “couplehood” is present by the use of the words “WE” and “I”. It is through using these particular words when referring to their spouses that we see the “coupleness” identified (Kaplan,

2001). This gives a very discrete view on a private relationship and was very evident in the interview transcripts (Carers 3 and 7).

However, there were times when the use of distancing language, “THEY”, was evident suggesting a disruption in the usually close relationship between the carer and the cared for, that I was privileged to hear. Here the term ‘they’, used by Carer 5, highlights his perception of what was to come, the loss of his wife that he knew and loved, his anger and frustration.

“see the people in similar situations they’re all the same you know, you can see the couples, you can see which one it is suffering you know, they can’t help it it’s not their fault but you know, they tend to get that sort of look about them” (Carer 5a, p 106-108).

10.3.2 Connection.

Connections with others offers profound physical and emotional benefits (Buckley & McCarthy, 2009). Ill health and cognitive decline suggest the help of others to maintain these connections for us is required. How this happens has been the subject of recent research as the focus on carers and their lived experiences increases (Youell *et al.*, 2016; Evans & Lee, 2014). These connections will differ from person to person. It may be that providing regular meals or making sure someone has the clothes on they would like to wear (Fjellstrom *et al.*, 2010) is how a connection to their wives is ensured. For other couples, the connection between husband and wife is subtler and more deeply felt (Carer 3 p116).

Whilst much of the research already highlighted discusses marital closeness and couplehood, it also shows how complex relationships can be between husband and wife. All of the literature discussed is trying to unpick and give a label to how these relationships work when in fact all of the subtlety and intermingling of the concepts are present in the relationships represented. This premise strongly supports the idea that looking at the carers' lived experience as separate from the 'cared for' experience does not enhance our knowledge of the experience but in fact separates and polarises something that is, by its very being, a joint or embedded experience. We have carers who are husbands, who are fathers to their children, who are brothers to their siblings, who are work colleagues, who are friends, etc. all of which occur simultaneously in a social context.

In the case of the persons with dementia, these connections are sometimes lost as the disease progresses. For the men in MaCE, adjusting to this loss of companion, friend, partner, for example, through a loss of shared interests, a loss of communication etc. is further complicated by the remaining physical presence of their wife (Wawrziczny *et al.*, 2016). Conceptually, this is difficult to cope with (Boylstein & Hayes, 2011). One's understanding of the person now is in stark contrast to how they used to be. A visible embodiment of the person as they were is present physically, but the behaviour of how they are now is in contrast to these memories and past behaviour. If the same social construct of a wife by gender socialisation and femininity is used, then the changing behaviour and decline in the person's cognition portrays a person who is no longer a wife (Wood & Eagly, 2015). The loss of connection with their wives was something all of the carers voiced during their interviews; for some, this was a loss of conversation and interests, for others, it was lost intimacy and closeness. The loss of this

connection was one of sadness and regret. For those carers who were caring for someone with dementia, the ongoing decline of cognition and communication with increased physical disability, made caring for them emotionally hard and physically demanding. For those carers whose wives had cancer, (Carers' 2,4 and 8), the increased physical decline whilst demanding in practical terms, still allowed for the connection between the couple of shared interests, communication and shared memories to sustain them. (Ho, 2008) An overall sense of identity, agency and selfhood through connections with others is prioritised over personal autonomy (Ho, 2008). This is evidenced in the findings of the MaCE study as the men took on the role of advocate for their wives. Maintaining a sense of identity for their wives, and a sense of self-hood for those with dementia, was further evidence of the connection and closeness with their wives that they were trying to maintain. When these elements of closeness and connection during a relationship break down, it appears that a sense of isolation and loneliness becomes apparent. These important findings of MaCE, the essential maintenance of connection and closeness of interactions with others, increases our knowledge and understanding of isolation and loneliness for informal male carers.

10.3.3 Isolation and loneliness.

The issues of isolation and loneliness, (see Background; Chapter 1,) has had recent exposure in society's understanding of our aging population today. The political and economic reasons for this are at the forefront of government policy and rhetoric within society as a whole. With this backdrop, it was surprising to see that whilst the carers in this study did experience isolation and loneliness, what

they described was very subtle and not the dichotomy one would imagine from the claims of the rhetoric. It was also surprising to see that having identified this issue from the men's conversations, it was not the all-consuming problem for the men interviewed that recent research and the media have portrayed.

Carer 6 was asked if he was lonely and replied, "no". This was surprising as this was not the response that previous literature suggested, and was not consistent with the feelings of the other men. He equated having the support of friends nearby as the reason why he was not lonely. However, during his interview he recalled having to stop attending his monthly model railway enthusiast club, because his wife did not want him to go. This change in behaviour could be seen as isolating in the longer term as he was reducing his contact with friends and stopping a hobby that was important to him. The wishes of his wife were more important to him than his need for his own interests. It is suggested that pleasing one's wife is preferable to the loss of masculinity (Gast & Peak, 2010; Ho, 2008). Pursuing his own needs by maintaining contact with friends, in this case going out when she did not want him to, may have reduced his objective experience of social isolation, but may also have increased his experience of loneliness as his relationship with his wife and the subsequent loss of connection and couplehood the resulting arrangement. This behavior of pleasing his wife could be seen as an example of the gendered social construct of male identity in the role of protector and provider (Robinson *et al.*, 2014; Robinson *et al.*, 2005). Protecting his wife from distress, in this case how she feels when he leaves her, acts as the driving value behind his action.

The experience of isolation and loneliness was an expectation of ageing for Carer 5 (pg 117). He did find the loss of friends and the disappointment in the support he received from his family upsetting and his emotional response to this was to cry. His experience of these lost friendships and connections with his family and friends further explains the subtlety of this subjective experience. He also describes a loss of status publicly when he and his wife moved to a smaller home; perhaps itself leading to a sense of increased loneliness. When situations change, as in ill health, it could be argued that a public isolation and change in identity are expressed as loneliness. Another influencing factor to the experience of isolation may be the extent to which a lack of support within the decision-making process and the need for help seeking is experienced (Baxter & Glendinning, 2013). For men, as we have seen in the previous discussion on help seeking and decision making, experiences of loneliness may be the by-product of a gendered role and identity.

One of the most poignant experiences recalled was by Carer 3 (p 88). He described his life-long love of classical music and going to concerts. He and his wife still went to as many concerts as they could but due to her challenging behaviour, where they sat had changed. He could no longer access seats in with other concert goers, as her need to sing or sway was disrupting for others. He had to choose seats in the balcony away from others at the back so she could stand up when she wanted to. This is an example of the subtlety of loneliness in this lived experience for this carer. He is getting out with his wife but how that is managed has changed. Despite the fact that they go out to concerts and meet people and are therefore not objectively socially isolated, how they go out and

what is needed to make that happen suggests the reverse. Maintaining this connection, however difficult, with his wife and their shared interests highlights the subtlety of an experience of disconnection from a social group i.e. concert/theatre goers. This need for conformity as demonstrated by the social psychological process (Mansfield *et al.*, 2003) suggests that men need conformity to a group more than women, and whilst caring for his wife, this exclusion from the concert/theatre goers could be experienced as loneliness.

Carer 4's experience of isolation and loneliness was voiced in terms of personal history. He went to great lengths to explain his upbringing, being an only child, his schooling at a grammar school with few friends, to adulthood and a career full of self-reliance and independence. From what we know of the gendered role of masculinity and some of the personality or cultural traits afforded to this role, his explanation of his caring for his wife with cancer was seen through this lens. The episodes of being alone were how, they as a couple, managed their marriage. His isolation from his family was a geographical norm as he worked overseas for his entire career. This personal history is what he brought to the role of carer and so the new skills he needed for this and the new situation he found himself in were addressed in a very pragmatic and resourceful way. He did allude to his lack of friends but dismissed this as an experience of loneliness. To have few friends was not uncommon for him as his personal history revealed.

A sense of loneliness pervades some of these examples given and as seen on one level, the men are getting out and doing the things that need doing but at a cost. This simplistic and objective view of behaviour however, may not be helpful

in understanding the experience of others as it clouds our understanding with a judgement on that behaviour. Whilst every effort was made during this study not to judge the experience of others, the feelings generated by the emotional content of the experiences recalled were difficult to isolate from the empathy and compassion of the researcher (Gallese, 2003). This binding identity of us to each other is why understanding of others experiences is so important. Separating an issue from those experiencing it, by those who are trying to understand it, is perhaps difficult and complex than it would seem.

Having discussed the issues of social isolation and loneliness as findings from MaCE, the temporality of these experiences should be considered as a dimension consistent with Heidegger's phenomenology that underpins this study. As highlighted in the methodology section of this thesis, Heidegger, states that temporality, the experience of time and its passing, is central to our existence in the world (Heidegger, 1926). The findings from MaCE suggest that the experience of social isolation and loneliness for these carers was present but not an experience that changed hugely over the research time, in effect nine months. When the interviews were conducted, the men highlighted initial changes in their situation as their wives were diagnosed with cancer, recurring disease, and changes in treatment for those with cancer in particular. At these time points, the men could highlight changes in support and friendships, and practical changes they needed to adapt to as the needs of their wives changed. These time points did bring feelings of loneliness by evidence of small and subtle changes. For those carers supporting their wives with dementia, the temporality of their experience of social isolation and loneliness appeared unchanged. Whilst they

acknowledged the physical needs of their wives had changed slowly over time, the underlying initial cognitive changes were the drivers of their feelings of social isolation and loneliness. This finding is very subtle in the light of current understanding of male carer experience. It appears that the initial cognitive decline, seen over many years in some of the carers accounts, was managed by their family and friends. At the point of diagnosis however, the carer experienced changes in friendships and family relationships, and a sense of social isolation and loneliness pervades the accounts of their lived experiences. This longevity of caring associated with the cognitive decline seen in dementia, highlights the experiences of social isolation and loneliness as discussed in this thesis.

10.3.4 Poems

The first of the two poems given to me as researcher by the carers was one that Carer 3 had found on the internet. It was written by a nurse and freely available. It was framed and clearly on view in the lounge. He found it very supportive as the quotes in Section 8.6.4 show. I feel the use of poetry in research is still largely uncommon. Biographical poetry or the use of poetry writing for therapy have been explored in psychology and sociology settings (Spiers & Smith, 2012). Whether writing or reading poetry, the benefits are well known (Hanauer, 2010). Poetry is seen as helpful in reconstructing complex experiences, as Hanauer identifies. Furman however, suggests that a poem creates an image that changes the passive nature of research into one of a co-creation of knowledge and understanding (Furman, 2004). The study of this narrative form enables empathy and understanding to be co-created between the carer and the researcher in this instance (Greenhalgh & Hurwitz, 1998). This understanding is generated by the

construction of meaning grounded in the lived experience, challenges perceived wisdom about a certain experience and enforces reflection on that lived experience by both the carer and the researcher. This use of an already written poetry, in the case of Carer 3's poem, suggests that difficult thoughts and feelings can be expressed by another 'without being any less true' (Greenhalgh & Hurwitz, 1998). From the discussion surrounding gendered language, from MaCE, it is assumed that words from another's perspective, could be used to understand and explain one's lived experience. Carer 3 found that these words could articulate his feelings more vividly than he could p80 (Eisner, 1997).

Carer 5 wrote his poem in memory of his wife and her feelings about her dementia. Similarly, this poem demonstrates the words of another. Hanauer (2010) suggests that poems capture illusion and in doing so distances reality. MaCE findings suggest however, that far from distancing the men from their situation, these poems in effect, have enabled them to understand the experience of their wives in a way that ensures advocacy and empathic understanding of what they were going through (Hanauer, 2010). It could be argued that Carer 5 is using this form of expression to provide the context and the perspective of his wife's suffering for all to hear. This eloquent poem engages the listener in the carers lived experience and invites interpretation from the researcher in line the phenomenological approach of this study (Greenhalgh & Hurwitz, 1998). The use of poetry to supplement data, as described by Spiers and Smith (2012), gives added richness to the data that encapsulates several aspects of an experience at once through metaphor and imagery (Spiers & Smith, 2012). The images from

these poems were a powerful account of the carers' situations, an example of the intimate understanding of and making sense of that situation.

The final section in the discussion of MaCE findings is the meaning men make of their friendships and support networks. This stems from the findings that all the men interviewed had many friends and as such described social inclusion and support from a wide range of agencies.

10.4 'Connecting friendship with support'

Friendship is something that is common across all cultures. We make friendships with those we have things in common with, for example values and beliefs, interests and common goals, and with those who have different interests and goals, abilities and views of life. Friendships are based on "quality, justice, and respect" p65 (Blatterer, 2015), and is an area of our lives that has been researched over the years. The link between friendships and well-being has been established and shows how important friendship and support is (Handley *et al.*, 2014). Friends have a part to play in maintaining good health and preventing some long term conditions such as depression (Holt-Lunstad *et al.*, 2010; Mead *et al.*, 2010). Studies have linked the numbers of friends with physical outcomes, as well as the absence of friends adversely affecting our individual lives and health, both physical and emotionally (Fratiglioni *et al.*, 2000; Mead *et al.*, 2010; van der Horst & Coffe, 2012). How we make these connections or friendships has been the source of examination by research and the findings suggests that there are two types of friends, those who offer "emotional sustenance" and those who offer "active coping assistance" (Thoits, 2011). This is an important thought when

we look at the conversations of the carers interviewed. The findings suggest that for the men in the MaCE study their friends and family did fall into these broad categories of practical and emotional support. There was no evidence to suggest that those friends who provided practical support were not also providing emotional support, but the men themselves had identified the different 'groups' of friends. It could be argued that this separation of friends could be the difference between friendship and support in the minds of those receiving it. However, differentiating between friendship and support, both terms used during the MaCE study, might be an example of this separation of friends as identified here by the literature examined.

Drawing on the earlier discussion surrounding the language men use when describing their experiences of being a carer (Seale & Charteris-Black, 2008), it could be assumed that men would describe a friend in terms of shared interests, and practical attributes and not by the use of emotional language. Using the premise of the two types of friends it could be argued that all men's friends would fall into the 'active coping assistance' bracket if the stereotypes and gendered roles of masculinity were adhered to (Thoits, 2011). However, a subtler element to friendship was seen with the identification and difference attributed between old friends and new friends. Whilst old friends come with a shared history and companionship over many years it appears that the making of new friends "here and now" is of equal value Carer 5 and 6 (p125). Therefore, a shared experience connects friends as well as shared history.

For Carers 5 and 6, the identification of new friendships made during this period of ill health was a surprise to them and a positive occurrence. They both attached value to these new friendships. To be with others who have experience of what you are going through allows for a shared understanding and unspoken acceptance of the situation. A sense of belonging is produced by mutual understanding, something we know that is very important to men as they find themselves caring for their wives in ill health (Mansfield *et al.*, 2003).

Two of the carers interviewed were still working (Carers 2 and 3, p125), and their interviews suggested that they were supported by work colleagues. This enabled them to have time away from work when they needed it to attend clinics and appointments without any problems. Flexible working patterns also enabled them to combine working and caring. This unspoken support of work colleagues was highlighted as important for Carer 4 (p129 second quote). A private acknowledgment of a private situation was vital in preserving a sense of normality when the uncertainty of his wife's cancer was ongoing.

Carer 2 (p 127) was the first to voice the difference he experienced between his female colleagues at work and his male colleagues; he experienced more regular questioning of his wife's health and well-being from his female colleagues than from his male colleagues. This experience ties in with the gendered values of stoicism and independence that maintains masculinity during social interactions with other men. However, at times he was grateful for the more emotional interaction and interest he had from his female colleagues. These contrasting supportive styles maintain the gendered approaches to ill health and caring that

have origins in the social construct of masculinity whilst the occasional emotional interactions enhance a deeper sense of connectedness with others.

The loss of friendships was a theme that emerged from the findings of the MaCE study. This loss was felt by the carers of those with dementia, and for them both as a couple. Although some loss of friendship and family support was evident for all the carers interviewed, it was felt most acutely by Carer 5. The loss of a particular close friend of his wife, as his wife's condition deteriorated, was a great source of frustration and anger to him. He was angry that this woman had not maintained her friendship with his wife during her ill health. When outlining the loss of his friends, he made sense of this by minimising the problem, and acknowledging the practical difficulties involved in maintaining normal contact as he would have in the past. The loss of 'hoped for' support from his family was expressed in terms of disappointment. Trying to make sense of these losses was emotional for Carer 5 as he tried to understand others reactions to his and his wife's situation. The sadness in his voice heard during the interview was emotional and powerful aspect of life for him to recall.

Several of the men highlighted the changes in the way they experienced friendship and support as they cared for their wives in ill health. Friendships that were usually conducted face to face were now confined to telephone calls as leaving the home became more difficult for those with wives with dementia. For those caring for their wives at home, the practical investment needed to attend clinic appointments with consultants, attend hospital wards for treatment regimes, and be at home for appointments with other healthcare professionals meant that maintaining friendships was difficult.

Support was described differently by the men who were not working. They focused on practical support, as already mentioned, but identified this as coming from a wider network of social connections. This support came from the local community.

For Carer's 7 and 9 the local church was a source of comfort and support for them as a couple. Acceptance of their wives with dementia was important and enabled them to get spiritual support for themselves at their time of need as they continued to attend the churches they had frequented.

For Carer 5, the local hairdresser was somewhere he could take his wife, maintaining her dignity and sense of self as the disease progressed. This had been important to her and maintaining this routine was important for her husband and the value he attached to her memory and wishes. Another source of support for Carer 5 was the local pub where he and his wife enjoyed being with their local friends. This support however, was also seen as a burden to him, as his wife wanted to go every evening, and he did not. This example was further evidence of personal autonomy being deferred in the pursuit of another's happiness, but also of the changing needs of carers.

What we can see from the men's interviews is that friendship and support are closely intertwined in the minds of those receiving it and also those giving it. Friends can offer emotional and practical support and more formal support networks, such as churches and healthcare services, can also offer emotional and practical support. Some might see friendship as the preserve of those we know well, with whom we share a history or with whom we share our thoughts and feelings with. Gendered language, that reinforces views and beliefs, is

alienating male carers/husbands from how they see themselves. Asking about support networks for men in a more neutral language may help them identify themselves with a service that fulfils their need for practical support. A befriending service on the other hand may do the opposite.

For those caring for someone with dementia the role of friendship and support was threefold; the men were maintaining friendships for themselves, for their wives and for themselves as a couple. All three of these processes need attention, energy and emotional investment to maintain. It is testament to the importance placed on friendships and support, however they were experienced by the men in MaCE, that makes understanding their experience vital if we are to provide timely and effective interventions when needed.

11 Conclusion

The findings from this research are both expected and surprising; expected because the experiences of the men interviewed identified known stresses and difficulties with caring for someone 24 hours a day, in terms of practical issues and the impact this had on their own health. Some findings such as identity, self as spouse, friendship/support, and the subjective experience of loneliness and social isolation were surprising. Assumptions that society attributes to caring paints a picture of it being burdensome, a negative experience, a lonely role, and one of changing dependence that the cared for submit to at times. This was not the case for the men interviewed; they highlighted the commitment and ongoing value attributed to their situation, to the continuity of marriage and to the changing connections that occur between a husband and a wife. The breadth of the

experiences of caring for those with cancer and/or dementia was demonstrated in all the themes identified. I felt that all the carers were open and honest with me in recalling their experiences, making the interviews intensely personal and touching. The carers were keen for others to know what being a carer meant to them and they tried to explain this to me. They are husbands first and foremost; caring changes their sense of self; caring changes their relationships for those they are caring for and friends and family. The caring experience of the male carers are complex. A plethora of feelings, emotions, beliefs, skills, and understanding make up these experiences. The sensations, thoughts and actions happen continuously, and simultaneously for these men. The term, 'lived experience' used in the published literature, suggests that it is 'one thing' that is experienced. In reality the 'experience' of caring for someone with cancer and/or dementia cannot be distilled into one experience. This experience is complex and influenced by many experiences that make up caring for someone. Relational frame theory suggests that experiences seen as a frame of equivalence e.g. A=B or old=lone, narrows our understanding of a given experience and in so doing, reduces the options available for support (McHugh, 2015). If the experience is described as a frame of hierarchy, e.g. A is part of B (caring is part of being a husband) rather than a frame of equivalence ('husband' and 'carer' are different things), further opportunities for support present themselves. Looking at experiences in this way suggests a wider perspective and gives a greater breadth of options when supporting someone who is caring for someone. An example of this would be that if someone doesn't identify themselves as a 'carer', then services that are targeted at 'carers' will not resonate with them for help and support. However, if the frame of equivalence is moved to a frame of hierarchy,

then those caring for someone may begin to see the benefits and similarities in their experiences that identifies them with another label (caring is part of being a husband) and in so doing opens up more avenues for support from caring agencies.

The strength of feeling and emotion present in the experiences recalled suggest that using an alternative approach to understand a complicated picture, gives clarity to that picture, and as such allows greater understanding of the experiences. For the husbands interviewed, maintaining 'being with' their wives, was rooted in their identity, more so than an objective sense of 'being a carer'. For most of the carers, giving examples of their relationships with their wives, does seem to have elicited feelings of 'husband' and not 'carer', even in ill health. These changes are experienced when 'being with' becomes caring for'.

12 Challenges and Limitations of the Study

At the start of MaCE, there were two major challenges experienced by the researcher. The first challenge was the experience of 'gatekeeping' from professionals, both healthcare and third sector managers, towards the recruitment of participants for the research. The second challenge was finding the research population, in this case men caring for those with advanced cancer and/or dementia at home.

The issue of 'gatekeeping' in health and social care research has been explored many times in recent years. A reluctance by professionals to engage in research recruitment can be attributed to concerns about burdening the patient, burdening the patients families, logistics of being involved in the recruitment when the

demands on professional's time are already high, and the value or benefit of the research study proposed (Kars *et al.*, 2016). Highlighting a protective bias in some healthcare professionals was seen that leaves vulnerable groups without a say in their needs (Rose *et al.*, 2017). The idea that research is burdensome to families whilst denying a choice for those who may wish to participate is also denying the benefits of taking part (Ellard-Gray *et al.*, 2015). The findings of MaCE show that those who took part did so because they wanted others to benefit from their experience and to be of help in the future.

An additional aspect of 'gatekeeping' arose from the local ethics committee reviewing the study. Excluding the researcher from the recruitment phase of a study due to perceived coercion concerns, potentially hampers the recruitment of participants to any study. The initial relationship built up with the research population by the researcher greatly increases recruitment to a study and there is strong evidence to suggest that this is a vital part of the recruitment strategy (Kars *et al.*, 2016; Bonevski *et al.*, 2014). This pre-recruitment relationship building (Ellard-Gray *et al.*, 2015) suggests not only an increase in the participation in the research study, but also an increase in the openness and honesty in their responses, based on a mutual relationship between the participants and the researcher. When developing research study's that explore potentially sensitive issues, such as living with dementia, end of life care or advancing disease, it could be argued that an empowering and inclusive relationship between the researcher and the population being researched, is essential if the views and needs of those being researched are to be accurate and fulsome.

Turning to recruitment challenges, the reason why men were chosen for MaCE was largely due to the paucity of research into men's experiences and has highlighted a 'hard to reach' population (McDaniel, 2003). The difficulty men had in identifying themselves with the title 'carer' may in part have explained the recruitment difficulties. Combined with their reluctance to seek help (Moller-Leimkuhler, 2001), their sense of masculine identity, their role and responsibilities (Mansfield *et al.*, 2003), researching the needs of male carers is problematic on many levels (Russell, 2016; Morbey *et al.*, 2013). The continued challenge of engaging men in research illustrates that despite MaCE recruiting a significant number of men, those that are not reached, those struggling and those not captured by the recruitment strategy, are denied a voice. The challenge for research recruitment teams is how to reach those who are lost to this prescriptive process. Innovative ways of capturing those whose voice is not heard need to be considered. Some prospective ideas on recruitment and engaging men in research are highlighted in Section 17, Recommendations.

MaCE is not without limitations. All the men in the MaCE study were married, and in heterosexual relationships. The purpose of the recruitment strategy was to recruit as diverse a population as possible within the criteria for the study. Despite the wide inclusion criteria used to recruit men for the study, this homogenous group consented and participated in the study. The sampling method used for recruitment was consistent with the theoretical underpinnings of the study and this homogeneity may be seen as an anomaly.

The rural setting where the men lived may be a limitation to the adoption of the findings for those in urban areas. Whilst the counties where the research took

place are rural, all the men were resident in the local towns and were not geographically isolated from friends, family, or services in this instance. Despite the rural nature of the counties, the men recruited for MaCE may not represent those living in more geographically isolated situations, and as such their experience of loneliness and isolation in particular, may not be generalised to the urban settings.

Having one female researcher for this study may also be seen as a limitation. As it has been shown throughout the discussion of the findings, gendered beliefs, ideas and assumptions influence the experiences of the male carers. It may have been helpful to have had an additional male colleague to conduct interviews and build different relationships with the men recruited. However, being the only researcher allowed me to visit the men in the study, building up a relationship with them and developing a rapport as the research timeframe continued. My clinical experience of dealing with distressed family members, and my widespread and extensive experience of dealing with people in all places, situations, faiths and cultures, gave me the skills to achieve truthful and in-depth data from the men in the study. The identification of the themes that were generated and the rigorous supervision of the running of the study and its design, ensured that any bias ensuing from a single researcher was minimised, and if suspected, acted on in the analysis phase. For example, a selection of transcripts and subsequent interpretation were scrutinised by my academic supervisors to ensure consistency and transparency of approach.

13. Recommendations for Health and Social Care Professionals

The results from the MaCE study identify three important recommendations for those who support carers by service provision and service delivery:

Firstly, widening the recruitment processes to engage men in research, is recommended. Having highlighted the gender issues surrounding male carers for the individual and society as a whole, a starting point for engaging men in research, may be a change in the language used when exploring carer experiences i.e. do not use the word, carer. Recruiting men for this study was difficult as has been discussed. Having identified that men sometimes find it difficult to see themselves as carers, then involving carer support providers, such as regional Carers' Trusts and disease specific carer groups in the recruitment process may not capture those who do not identify with 'the carer' label. Perhaps information in the form of flyers and posters could have been placed in other locations such as pubs, churches, and supermarkets. In addition, using sports facilities or clubs to highlight the research study may have reached a younger population who could then have identified a grandfather, father, brother, or uncle, that may have been interested. Although the demographics for carers are generally situated in the older sections of society, the benefits of involving the younger generation, whilst engaging with them in the issues surrounding the care of those with dementia and/or cancer, may also have reached additional men whose voice was lost by the conventional recruitment streams. It may also have been beneficial to include local secondary schools and colleges, for the same reasons, in identifying potential men for this study. The use of social media for recruitment has been explored in recent years, and whilst I do think it has a place

in recruitment, the use of social media for data collection contradicts one of the important observations from the MaCE study - talking to a researcher helped the men verbalise, make sense of, explain, explore and validate their lived experiences. From the field of enquiry to the research question itself, gender neutral, inclusive, and compassionate language need to be present.

A second recommendation is around the use of the word 'carer'. As previously discussed, the men interviewed in the study did not associate themselves with the term 'carer' whilst they cared for their wives. Identifying themselves with the title, 'husband' rather than carer, may limit their awareness and access to services, practical support, professional input in their wife's care, support groups. Identifying themselves with the term, 'carer' however, is to potentially challenge their sense of identity, their role and responsibilities, their sense of self, for example, that may make coping with a change in their role problematic to adjust to. By changing the use of the word 'carer', to identify someone by a title or label, to the word caregiver, the status of what is referred to, has changed. As shown above, the labels that we attach to ourselves and what that role is, are often socially constructed in an exclusive way. By using the term 'carer', an exclusive identity of that role is formed. As discussed in Chapter 14, the attributes and identity attributed to a particular title can be unhelpful and helpful. This disparity or blurring of identities produces the dissonance one experiences when identifying with a particular title or label. This is a direct finding of MaCE as the term carer was not favoured by the men. By using the term 'caregiver' a more inclusive word is used that promotes a more socially accepted role.

The third recommendation from MaCE is to include a psychological understanding of the changes that caring for someone brings about. The extent to which the men displayed changing behaviours and relationships in the pursuit of this caring role over time suggest this is needed. Having considered one of the ways in which behaviour can be understood through a CBS model, this contemporary psychological approach of making sense of behaviour may inform a conversation designed to help support carers in their role. Traditionally, help for carers has focused on disease information and education; practical implementation and awareness of services; information on respite options in the form of daycare; short stay admissions and sitting services. This continued polarisation of the practical needs of carers from the needs of those that are cared for, may have contributed to the feelings of isolation and loneliness identified in the findings of this study.

A different approach that may help and support those caring for someone at home may be Acceptance and Commitment Therapy (ACT). Whilst the use of the word 'therapy' in this mindfulness-based approach identifies its clinical usefulness and development for those struggling with life events, its core strategies can be used to develop psychological or coping strategies for all of us (Harris, 2007; Hayes *et al.*, 2013; Owen, 2011).

By using a mindful approach to our thoughts and feelings, one can develop the psychological flexibility that allows one to live a more value based and fulfilling life. As discussed in the gender section of 'when being with becomes caring for' section 12.4, and in section 12.5 exploring 'a sense of self', holding on to rigid

rules and beliefs about ourselves can stop us behaving in the valued way we would want to. Applying ACT (Hayes *et al.*, 2006; Owen, 2014) a particular approach and understanding to our thoughts, emotions and beliefs, as well as our life experiences, interactions with others may change our thoughts and behaviour in our caring role even though the underlying source of sorrow and difficulty (the changes in a loved one and in one's own life) cannot themselves be reversed.

The six core principles for ACT are;

- Defusion - this is the ability to distance ourselves from unhelpful thoughts or self-criticisms
- Expansion - by noticing and allowing the presence of unpleasant thoughts and feelings one is less likely to be held back or influenced by them
- Connection - this is the ability to fully engage in the moment, what is happening here and now, not what did happen or what may happen in the future
- The observing self- this is the part of our mind that notices all that happens to us allowing us to experience everything, thoughts feelings emotion etc. that connects us to the here and now
- Values- these are the actions and beliefs that are most important to us, for example caring for our loved ones, providing for our families
- Committed actions- this is another way of describing the value based behaviour that defines our lives to create a meaningful life

By using this approach, we can help others develop mindfulness skills, that can change behaviour in the face of stress, loss, disappointment, loneliness and isolation, sense of self, and self as spouse, some of the experiences associated with the findings of the MaCE study. This approach used in collaboration with disease information, practical services, and support for those being cared for from professionals may enhance the experience of carers. By adopting a specific programme on the benefits of psychological care, ACT, the emotional support for male carers may be met in a way they hitherto have not been.

14. Implications for Future Research

The findings of MaCE show that the relationship between the carer and the cared for, whatever that relationship may be, influences the care given and that in turn changes the nature of the couple's relationship. Whilst it is always the intention of research to add to existing knowledge and MaCE study does this in the areas of social isolation and loneliness, there are inevitably questions left unanswered. The issue of loneliness and isolation and how carers are changed by caring, requires constant and detailed examination by existing research methods. The context for this continued research should include the experiences of different carers of different cultures, the experience of caring for same sex couples, co-habiting couples and non-spousal carers not covered by MaCE. The understanding of the lived experience of carers in the context of their caring role must remain central to the research design.

15. References

- Abma, T. A. (2002) Emerging Narrative Forms of Knowledge Representation in the Health Sciences: Two Texts in a Postmodern Context. *Qualitative Health Research*, 12 (1): 5-27.
- Addington-Hall, J. Fakhoury & W. McCarthy, M. (1998) Palliative Care in nonmalignant Disease. *Palliative Medicine*, 12 417-427.
- Age UK (2009) Loneliness and Isolation Evidence Review.
- Albinsson, L. & Strang, P. (2003) Existential Concerns of Families of Late-Stage Dementia Patients: Questions of Freedom, Choices, Isolation, Death, and Meaning. *Journal of Palliative Medicine*, 6 (2): 225-236.
- Alzheimer's Society UK (2013) Dementia the Hidden Voice of Loneliness. 1-7.
- Andren, S. & Elmstahl, S. (2008) The relationship between caregiver burden, caregivers' perceived health and their sense of coherence in caring for elders with dementia. *J Clin Nurs*, 17 (6): 790-799.
- Avdela, E. (1999) Work, Gender and History in the 1990s and Beyond *Gender and History*, 11 (3): 528-541.
- Bainbridge, D., Krueger, P., Lohfeld, L. & Brazil, K. (2009) Stress processes in caring for an end-of-life family member: application of a theoretical model. *Ageing Ment Health*, 13 (4): 537-545.
- Barnett, R. C. & Hyde, J. S. (2001) Women, Men, Work, and Family *American Psychologist*, 56 (10): 781-796.
- Barnett-Page, E. & Thomas, J. (2009) Methods for the synthesis of qualitative research: a critical review. *BMC Med Res Methodol*, 9 59.
- Baxter, K. & Glendinning, C. (2013) The Role of Emotions in the Process of Making Choices about Welfare Services: The Experiences of Disabled People in England. *Social Policy and Society*, 12 (03): 439-450.
- Beach, B. & McKenzie, D. (2014) Population Ageing and the Voluntary Sector: Key Figures and Projected Trends. *Commission on the Voluntary Sector & Ageing*,
- Beeson, R., Horton-Deutsch, S., Farran, C. & Neudorfer, M. (2000) Loneliness And Depression In Caregivers Of Persons With Alzheimer's Disease Or Related Disorders. *Issues in Mental Health Nursing*, 21 779-806.
- Bengtson, V. L. (2001) Beyond the Nuclear Family: The Increasing Importance of Multigenerational Bonds. *Journal of Marriage and Family*, 63 1-16.

Berne, E. (1964) *Games People Play: The Psychology of Human Relationships*. New York: Grove Press.

Biggerstaff, D. & Thompson, A. R. (2008) Interpretative Phenomenological Analysis (IPA): A Qualitative Methodology of Choice in Healthcare Research. *Qualitative Research in Psychology*, 5 (3): 214-224.

Blatterer, H. (2015) Intimacy as freedom. *Thesis Eleven*, 132 (1): 62-76.

Boland, D. L. & Sims, S. (1996a) Family Caregiving at Home as a Solitary Journey. *Journal of Nursing Scholarship*, 28 (1): 55-58.

Boland, D. L. & Sims, S. L. (1996b) Family Care giving at Home as a Solitary Journey. *Journal of Nursing Scholarship*, 28 (1): 55-58.

Bonevski, B., Randell, M., Paul, C., Chapman, K., Twyman, L., Bryant, J., Brozek, I. & Hughes, C. (2014) Reaching the hard-to-reach: a systematic review of strategies for improving health and medical research with socially disadvantaged groups. *BMC Med Res Methodol*, 14 42.

Boyer, K., Dermott, E., James, A. & MacLeavy, J. (2017) Men at work? Debating shifting gender divisions of care. *Dialogues in Human Geography*, 7 (1): 92-98.

Boylstein, C. & Hayes, J. (2011) Reconstructing Marital Closeness While Caring for a Spouse With Alzheimer's. *Journal of Family Issues*, 33 (5): 584-612.

Bramble, M., Moyle, W. & McAllister, M. (2009) Seeking connection: family care experiences following long-term dementia care placement. *J Clin Nurs*, 18 (22): 3118-3125.

Brayne, C., Gao, L., Dewey, M., Matthews, F. E., Medical Research Council Cognitive, F. & Ageing Study, I. (2006) Dementia before death in ageing societies--the promise of prevention and the reality. *PLoS Med*, 3 (10): e397.

Broome, S. (2016) The Missing Million: In Search of the Loneliest in our Communities. *Campaign to End Loneliness*,

Buckley, C. & McCarthy, G. (2009) An Exploration of Social Connectedness as perceived by Older Adults in a Long-Term Care Setting in Ireland. *Geriatric Nursing*, 30 (6): 390-396.

Cain, R., McClean, M. & Sellick, S. (2004) Giving support and getting help: Informal caregivers' experiences with palliative care services. *Palliative and Supportive Care*, 2 265-272.

Calasanti, T. (2007) Taking 'Women's Work' Like a Man: Husbands experience of care work. *The Gerontologist*, 47 (4): 516-527.

Calasanti, T. & Bowen, M. E. (2006) Spousal caregiving and crossing gender boundaries: Maintaining gendered identities. *Journal of Aging Studies*, 20 (3): 253-263.

Campbell, R., Morgan, M., Daker-White, G., Britten, N., Pill, R., Yardley, L., Pope, C. & Donovan, J. (2011) Evaluating meta-ethnography: systematic analysis and synthesis of qualitative research. *Health Technology Assessment*, 15 (43): 1-164.

Carmichael, F. & G. Ercolani, M. (2014) Overlooked and undervalued: the caring contribution of older people. *International Journal of Social Economics*, 41 (5): 397-419.

Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J. & Neville, A. (2010) The Supportive care needs of family members of men with advanced prostate cancer. *Canadian Oncology Nursing Journal*, 166-170.

Cassell, C. & Symon, G. (2004) *Essential Guide to Qualitative Methods in Organisational Research*. London: Sage Publications

Clark, S., Prescott, T. & Murphy, G. (2017) The lived experiences of dementia in married couple relationships. *Dementia (London)*, 1471301217722034.

Coates, J. (2004) *Women, Men and Language: A Sociolinguistic Account of Gender Differences in Language*. 3rd edn. Harlow: Pearson.:

Corden, A. & Hirst, M. (2011) Partner care at the end-of-life: Identity, language and characteristics. *Ageing & Society*, 31 (2): 217-242.

Coventry, P. A., Grande, G. E., Richards, D. A. & Todd, C. J. (2005) Prediction of appropriate timing of palliative care for older adults with non-malignant life-threatening disease: a systematic review. *Age Ageing*, 34 (3): 218-227.

Crowston, K., Allen, E. E. & Heckman, R. (2012) Using natural language processing technology for qualitative data analysis. *International Journal of Social Research Methodology*, 15 (6): 523-543.

Davies, J. C. (2011) Preserving the “us identity” through marriage commitment while living with early-stage dementia. *Dementia*, 10 (2): 217-234.

De Silva, P. (1990) Buddhist Psychology: Review of theory and Practice. *Current Psychology*, 9 (3): 236-254.

Del Bono, E., Sala, E. & Hancock, R. (2009) Older carers in the UK: are there really gender differences? New analysis of the individual sample of anonymised records from the 2001 UK Census. *Health Soc Care Community*, 17 (3): 267-273.

Department of Health (2005) *Research Governance Framework for Health and Social Care*. London:

Department of Health (2010) *Carers and personalisation: improving outcomes*.

Department of Health (2017) Adult Social Care Outcome Framework 2017/2018.

Dickens, A. P., Richards, S. H., Greaves, C. J. & Campbell, J. L. (2011) Interventions targeting social isolation in older people: a systematic review. *BMC Public Health*, 11 647.

Dixon-Wood, M., Agarwal, S., Jones, D., Young, B. & Sutton, A. (2005) Synthesising qualitative and quantitative evidence: a review of possible methods. *Journal of Health Services Research and Policy*, 10 (1): 45-53.

Dowling, M. (2004) Hermeneutics: an exploration. . *Nurse Researcher*, 11 (4): 30-39.

Droes, R. M., Meiland, F. J., Schmitz, M. J. & van Tilburg, W. (2006) Effect of the Meeting Centres Support Program on informal carers of people with dementia: results from a multi-centre study. *Aging Ment Health*, 10 (2): 112-124.

Duggelby, W., Penz, K., Leipert, B., Wilson, D., Goodridge, D. & Williams, A. (2011) I am part of a community but.... The changing context of rural living for persons with advanced cancer and their families. *Rural and Remote Health*, 11 (1733):

Eatough, V. & Smith, J. (2010) The SAGE Handbook of Qualitative Research in Psychology Interpretative Phenomenological Analysis.

Egdell, V. (2013) Who cares? Managing obligation and responsibility across the changing landscapes of informal dementia care. . *Ageing & Society*, 33 888-907.

Eisner, E. W. (1997) The Promise and Perils of Alternative Forms of Data Representation. *Educational Researcher*, 26 (6): 4-10.

Ellard-Gray, A., Jeffrey, N. K., Choubak, M. & Crann, S. E. (2015) Finding the Hidden Participant. *International Journal of Qualitative Methods*, 14 (5): 160940691562142.

Etkind, S. N., Bone, A. E., Gomes, B., Lovell, N., Evans, C. J., Higginson, I. J. & Murtagh, F. E. M. (2017) How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Med*, 15 (1): 102.

Evans, D. & Lee, E. (2014) Impact of dementia on marriage: a qualitative systematic review. *Dementia (London)*, 13 (3): 330-349.

Farina, N., Page, T. E., Daley, S., Brown, A., Bowling, A., Basset, T., Livingston, G., Knapp, M., Murray, J. & Banerjee, S. (2017) Factors associated with the quality of life of family carers of people with dementia: A systematic review. *Alzheimers Dement*, 13 (5): 572-581.

Figueiredo, D., Jacome, C., Gabriel, R. & Marques, A. (2016) Family care in chronic obstructive pulmonary disease: what happens when the carer is a man? *Scand J Caring Sci*, 30 (4): 721-730.

Fine, M. & Glendinning, C. (2005) Dependence, independence or inter-dependence? Revisiting the concepts of 'care' and 'dependency'. *Ageing and Society*, 25 (04): 601-621.

Fine, M. & Spencer, R. (2009) Social Isolation. Development of an Assessment Tool for HACC Services. *New South Wales Department of Disability, Ageing and Home Care*,

Fjellstrom, C., Starkenberg, A., Wesslen, A., Licentiate, M. S., Tysen Backstrom, A. C., Faxen-Irving, G. & Omeg, A. D. S. G. (2010) To be a good food provider: an exploratory study among spouses of persons with Alzheimer's disease. *Am J Alzheimers Dis Other Dement*, 25 (6): 521-526.

Fratiglioni, L., Wang, H.-X., Ericsson, K., Maytan, M. & Winblad, B. (2000) Influence of social network on occurrence of dementia: a community-based longitudinal study. *The Lancet*, 355 (9212): 1315-1319.

Furman, R. (2004) Using Poetry and Narrative as Qualitative Data: Exploring a Father's Cancer Through Poetry. *Families, Systems, & Health*, 22 (2): 162-170.

Gallese, V. (2003) The Roots of Empathy: The Shared Manifold Hypothesis and the Neural Basis of Intersubjectivity. *Psychopathology*, 36 (4): 171-180.

Gast, J. & Peak, T. (2010) "It Used to Be That if It Weren't Broken and Bleeding Profusely, I Would Never Go to the Doctor": Men, Masculinity, and Health. *American Journal of Men's Health*, 5 (4): 318-331.

George, L. (1993) Sociological Perspectives on Life Transitions. *Annual Review Sociology*, 19 353-373.

Glick, P. (1995) The life Cycle of the Family. *Marriage and Family Living*, 17 (1): 3-9.

Global Burden of Disease Cancer, C., Fitzmaurice, C., Allen, C., Barber, R. M., Barregard, L., Bhutta, Z. A., Brenner, H., Dicker, D. J., Chimed-Orchir, O., Dandona, R., Dandona, L., Fleming, T., Forouzanfar, M. H., Hancock, J., Hay, R. J., Hunter-Merrill, R., Huynh, C., Hosgood, H. D., Johnson, C. O., Jonas, J. B., Khubchandani, J., Kumar, G. A., Kutz, M., Lan, Q., Larson, H. J., Liang, X., Lim, S. S., Lopez, A. D., MacIntyre, M. F., Marczak, L., Marquez, N., Mokdad,

A. H., Pinho, C., Pourmalek, F., Salomon, J. A., Sanabria, J. R., Sandar, L., Sartorius, B., Schwartz, S. M., Shackelford, K. A., Shibuya, K., Stanaway, J., Steiner, C., Sun, J., Takahashi, K., Vollset, S. E., Vos, T., Wagner, J. A., Wang, H., Westerman, R., Zeeb, H., Zoeckler, L., Abd-Allah, F., Ahmed, M. B., Alabed, S., Alam, N. K., Aldhahri, S. F., Alem, G., Alemayohu, M. A., Ali, R., Al-Raddadi, R., Amare, A., Amoako, Y., Artaman, A., Asayesh, H., Atnafu, N., Awasthi, A., Saleem, H. B., Barac, A., Bedi, N., Bensenor, I., Berhane, A., Bernabe, E., Betsu, B., Binagwaho, A., Boneya, D., Campos-Nonato, I., Castaneda-Orjuela, C., Catala-Lopez, F., Chiang, P., Chibueze, C., Chitheer, A., Choi, J. Y., Cowie, B., Damtew, S., das Neves, J., Dey, S., Dharmaratne, S., Dhillon, P., Ding, E., Driscoll, T., Ekwueme, D., Endries, A. Y., Farvid, M., Farzadfar, F., Fernandes, J., Fischer, F., TT, G. H., Gebru, A., Gopalani, S., Hailu, A., Horino, M., Horita, N., Hussein, A., Huybrechts, I., Inoue, M., Islami, F., Jakovljevic, M., James, S., Javanbakht, M., Jee, S. H., Kasaeian, A., Kedir, M. S., Khader, Y. S., Khang, Y. H., Kim, D., Leigh, J., Linn, S., Lunevicius, R., El Razek, H. M. A., Malekzadeh, R., Malta, D. C., Marcenes, W., Markos, D., Melaku, Y. A., Meles, K. G., Mendoza, W., Mengiste, D. T., Meretoja, T. J., Miller, T. R., Mohammad, K. A., Mohammadi, A., Mohammed, S., Moradi-Lakeh, M., Nagel, G., Nand, D., Le Nguyen, Q., Nolte, S., Ogbo, F. A., Oladimeji, K. E., Oren, E., Pa, M., Park, E. K., Pereira, D. M., Plass, D., Qorbani, M., Radfar, A., Rafay, A., Rahman, M., Rana, S. M., Soreide, K., Satpathy, M., Sawhney, M., Sepanlou, S. G., Shaikh, M. A., She, J., Shiue, I., Shore, H. R., Shrimme, M. G., So, S., Soneji, S., Stathopoulou, V., Stroumpoulis, K., Sufiyan, M. B., Sykes, B. L., Tabares-Seisdedos, R., Tadese, F., Tedla, B. A., Tessema, G. A., Thakur, J. S., Tran, B. X., Ukwaja, K. N., Uzochukwu, B. S. C., Vlassov, V. V., Weiderpass, E., Wubshet Terefe, M., Yebyo, H. G., Yimam, H. H., Yonemoto, N., Younis, M. Z., Yu, C., Zaidi, Z., Zaki, M. E. S., Zenebe, Z. M., Murray, C. J. L. & Naghavi, M. (2017) Global, Regional, and National Cancer Incidence, Mortality, Years of Life Lost, Years Lived With Disability, and Disability-Adjusted Life-years for 32 Cancer Groups, 1990 to 2015: A Systematic Analysis for the Global Burden of Disease Study. *JAMA Oncol*, 3 (4): 524-548.

Gomes, B. & Higginson, I. J. (2008) Where people die (1974-2030): past trends, future projections and implications for care. *Palliative Medicine*, 22 33-41.

Grady, C. (2015) Enduring and emerging challenges of informed consent. *N Engl J Med*, 372 (9): 855-862.

Grande, G., Stajduhar, K., Aoun, S., Toye, C., Funk, L., Addington-Hall, Payne, S. & Todd, C. (2009) Supporting lay carers in end of life care: current gaps and future priorities. *Palliative Medicine*, 23 339-344.

Greenhalgh, T. & Hurwitz, B. (1998) *Narrative Based Medicine. Dialogue and discourse in clinical practice*. London: BMJ Books.

Hanauer, D. A. (2010) *Poetry as Research : Exploring second language poetry writing*. John Benjamin's Publishing Company.

- Handley, S., Joy, I., Hestbaek, C. & Marjoribanks, D. (2014) The Best Medicine. The importance of relationships for health and well-being. *Relate*, 1-52.
- Harris, R. (2007) *The Happiness Trap*. London: Constable and Robinson Ltd.
- Haviland, W., Prins, H., McBride, B. & Walrath, D. (2011) *Cultural Anthropology: The Human Challenge*. 13th edition edn. Cengage Learning.
- Hayes, S. C., Barnes-Holmes, D. & Wilson, K. G. (2012) Contextual Behavioral Science: Creating a science more adequate to the challenge of the human condition. *Journal of Contextual Behavioral Science*, 1 (1-2): 1-16.
- Hayes, S. C., Levin, M. E., Plumb-Villardaga, J., Villatte, J. L. & Pistorello, J. (2013) Acceptance and Commitment Therapy and Contextual Behavioral Science: Examining the Progress of a Distinctive Model of Behavioral and Cognitive Therapy. *Behavior Therapy*, 44 (2): 180-198.
- Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A. & Lillis, J. (2006) Acceptance and Commitment Therapy: Model, process and outcomes. . *Psychology Faculty Publications*, (101):
- Hazra, N. C., Rudisill, C. & Gulliford, M. C. (2018) Determinants of health care costs in the senior elderly: age, comorbidity, impairment, or proximity to death? *Eur J Health Econ*, 19 (6): 831-842.
- Heidegger, M. (1926) *Being and Time*. 27 edn. Oxford: Blackwell Publishing.
- Hellström, I., Nolan, M. & Lundh, U. (2016) Sustaining 'couplehood' Spousal strategies for living positively with dementia. *Dementia*, 6 (3): 383-409.
- Henderson, J. (2001) 'He's not my carer—he's my husband': Personal and policy constructions of care in mental health. *Journal of Social Work Practice*, 15 (2): 149-159.
- Hennings, J., Froggatt, K. & Keady, J. (2010) Approaching the end of life and dying with dementia in care homes: the accounts of family carers. *Reviews in Clinical Gerontology*, 20 (02): 114-127.
- HM Government (2008) Carers at the heart of 21st century families and communities. .
- Ho, A. (2008) Relational autonomy or undue pressure? Family's role in medical decision making. *Scand J Caring Sci*, 22 128-135.
- Holt-Lunstad, J., Smith, T. & Layton, B. (2010) Social Relationships and Mortality Risk: A meta-analytic review. *PLoS Med*, 7 (7): 1-20.
- Hudson, P. & Payne, S. (2011) Family caregivers and palliative care: current status and agenda for the future. *J Palliat Med*, 14 (7): 864-869.

- Hudson, P. L., Remedios, C. & Thomas, K. (2010) A systematic review of psychosocial interventions for family carers of palliative care patients. *BMC Palliat Care*, 9 17.
- Jonsson, B., Hofmarcher, T., Lindgren, P. & Wilking, N. (2016) The cost and burden of cancer in the European Union 1995-2014. *Eur J Cancer*, 66 162-170.
- Jopling, K. (2015) Promising Approaches to Reducing loneliness and isolation in later life. *Age UK*,
- Kaplan, L. (2001) A Couplehood Typology for Spouses of Institutionalised Persons With Alzheimers Disease: Perceptions of "We" "I". *Family Relations*, 50 87-98.
- Kars, M. C., van Thiel, G. J., van der Graaf, R., Moors, M., de Graeff, A. & van Delden, J. J. (2016) A systematic review of reasons for gatekeeping in palliative care research. *Palliat Med*, 30 (6): 533-548.
- Knapp, M. & Prince, M. (2007) Dementia UK. The Full Report. *Alzheimer's Society*,
- Kramer, B. J. & Lambert, J. D. (1999a) Caregiving as a Life Course Transition Among Older Husbands: A Prospective Study *The Gerontological Society of America*, 39 (6): 658-667.
- Kramer, B. J. & Lambert, J. D. (1999b) Caregiving as a Life Course Transition Among Husbands: A Prospective Study. *The Gerontological Society of America*, 39 (6): 658-667.
- Kvale, S. & Brinkman, S. (2009) *Interviews Learning the Craft of qualitative Research Interviewing*. Second edn. Los Angeles: Sage
- Langdrige, D. (2007) *Phenomenological Psychology. Theory Research and Method*. Open University Pearson Education Limited.
- Larkin, M., Eatough, V. & Osborn, M. (2011) Interpretative phenomenological analysis and embodied, active, situated cognition. *Theory & Psychology*, 21 (3): 318-337.
- Lawrence, V., Samsi, K., Murray, J., Harari, D. & Banerjee, S. (2011) Dying well with dementia: qualitative examination of end-of-life care. *Br J Psychiatry*, 199 (5): 417-422.
- Leggett, A. N., Zarit, S., Taylor, A. & Galvin, J. E. (2011) Stress and burden among caregivers of patients with Lewy body dementia. *Gerontologist*, 51 (1): 76-85.

Liberati, A., Tetzlaff, J. & Altman, D. (2009) Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *Pubmed*, 6 (6):

Lloyd, L. & Jessiman, T. (2014) Support for older carers of older people: The impact of the 2014 Care Act. 1-10.

Lucas, P. J., Baird, J., Arai, L., Law, C. & Roberts, H. M. (2007) Worked examples of alternative methods for the synthesis of qualitative and quantitative research in systematic reviews. *BMC Med Res Methodol*, 7 4.

Macmillan Cancer Support (2017) *Cancer Statistics Fact Sheet*.

Mansfield, A., Addis, M. E. & Mahalik, J. R. (2003) "Why Won't He Go to the Doctor?: The Psychology of Men's Help Seeking *International Journal of Men's Health*, 2 (2): 93-109.

Matthews, B. A., Baker, F. & Spillers, R. L. (2004) Family caregivers' quality of life: influence of health protective stance and emotional strain. *Psychology & Health*, 19 (5): 625-641.

McCaffrey, N., Cassel, J. B. & Coast, J. (2015) Bringing the economic cost of informal caregiving into focus. *Palliat Med*, 29 (10): 866-867.

McDaniel, S. A. (2003) Hidden In The Household: Now It's Men In Mid-Life. *Ageing International*, 28 (4): 326-344.

McHugh, J., Wherton, J. P., Prendergast, D. K. & Lawlor, B. A. (2012) Identifying opportunities for supporting caregivers of persons with dementia through information and communication technology. *Gerontechnology*, 10 (4): 220-230.

McHugh, L. (2015) A Contextual Behavioural Science approach to the self and perspective taking. *Current Opinion in Psychology*, 2 6-10.

McHugh, L. & Stewart, I. (2012) *The Self and Perspective Taking. Contributions and Applications from Modern Behavioural Science*. Canada: Context Press.

McLean, K. C., Pasupathi, M. & Pals, J. L. (2016) Selves Creating Stories Creating Selves: A Process Model of Self-Development. *Personality and Social Psychology Review*, 11 (3): 262-278.

McNeil, C. & Hunter, J. (2014) The Generation Strain. Collective Solutions to Care in an Ageing Society. *Institute for Public Policy Research*,

McPherson, B. (2015) The Sandwich Generation Feels the Squeeze. *Franchising World*, 55-56.

Mead, N., Lester, H., Chew-Graham, C., Gask, L. & Bower, P. (2010) Effects of befriending on depressive symptoms and distress: systematic review and meta-analysis. *Br J Psychiatry*, 196 (2): 96-101.

Merrick, K., Camic, P. M. & O'Shaughnessy, M. (2016) Couples constructing their experiences of dementia: A relational perspective. *Dementia (London)*, 15 (1): 34-50.

Moens, K., Higginson, I. J., Harding, R. & Euro, I. (2014) Are there differences in the prevalence of palliative care-related problems in people living with advanced cancer and eight non-cancer conditions? A systematic review. *Journal of Pain & Symptom Management*, 48 (4): 660-677.

Moller-Leimkuhler, A. M. (2001) Barriers to help-seeking by men: a review of sociocultural and clinical literature with particular reference to depression. *Journal of Affective Disorders*, 71 1-9.

Molyneaux, V., Butchard, S., Simpson, J. & Murray, C. (2010) Reconsidering the term 'carer': a critique of the universal adoption of the term 'carer'. *Ageing and Society*, 31 (03): 422-437.

Molyneaux, V. J., Butchard, S., Simpson, J. & Murray, C. (2012) The co-construction of couplehood in dementia. *Dementia*, 11 (4): 483-502.

Morbey, H., Payne, S., Froggatt, K., Milligan, C. & Turner, M. (2013) Supporting Older Carers of those Nearing the End of life. .

Murray, S. A., Kendall, M., Boyd, K. & Sheikh, A. (2005a) Illness trajectories and palliative care. *British Medical Journal*, 330 (7498): 1007-1011.

Murray, S. A., Kendall, M., Boyd, K. & Sheikh, A. (2005b) Illness Trajectories and Palliative Care. *BMJ Open*, 330 (7498): 1007-1011.

National Council for Palliative Care (2013) Who cares? Support for carers of people approaching the end of life. .

Noone, J. H. & Stephens, C. (2008) Men, masculine identities, and health care utilisation. *Sociol Health Illn*, 30 (5): 711-725.

O'Brien, R., Hunt, K. & Hart, G. (2005) 'It's caveman stuff, but that is to a certain extent how guys still operate': men's accounts of masculinity and help seeking. *Soc Sci Med*, 61 (3): 503-516.

O'Connor, D. L. (2007) Self-identifying as a caregiver: Exploring the positioning process. *Journal of Aging Studies*, 21 (2): 165-174.

O'Sullivan, A. (2015) Pulled from all sides: The sandwich generation at work. *Work*, 50 (3): 491-494.

Oberg, B.-M. (2004) *Changing Worlds and the Ageing Subject. Dimensions in the study of ageing and later life*. Sweden: Routledge.

Owen, R. (2011) *Facing The Storm. Using CBT, Mindfulness And Acceptance To Build Resilience When Your World's Falling Apart* Hove, East Sussex: Routledge

Owen, R. (2014) *Living With the Enemy. Coping with the stress of chronic illness using CBT, mindfulness and acceptance*. Abingdon: Routledge.

Parsons, K. (2010) Exploring how Heideggerian philosophy underpins phenomenological research. *Nurse Researcher*, 17 (4): 60-69.

Polit, D. & Tatano Beck, C. (2004) *Nursing Research Principles and Methods*. USA: Lippincott Williams and Wilkins.

Popay, J., Rogers, A. & Williams, G. (1998) Rationale and Standards for the Systematic Review of Qualitative Literature in Health Services Research. *Qual Health Res*, 8 (3): 341-351.

Prakke, H. (2011) Spousal relationships in which one partner has early cognitive problems. *Dementia*, 11 (2): 199-215.

Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A., Wittenberg, R., Adelaja, B., Hu, B., King, D., Rehill, A. & Salimkumar, D. (2014) *Dementia UK: Second edition and overview*.

Proot, I., Abu-Saad, H. H., Crebolder, H., Goldsteen, M., Luker, K. & Widdershoven, G. (2003) Vulnerability of family caregivers in terminal palliative care at home: balancing between burden and capacity. *Scandinavian Journal of Caring Science*, 17 113-121.

Public Health England (2013) *National Survey of Patient Activity for Specialist Palliative Care Services*.

Reid, K., Flowers, P. & Larkin, M. (2005) Exploring lived experience. *The Psychologist*, 18 (1): 20-23.

Reinke, L. F., Engelberg, R. A., Shannon, S. E., Wenrich, M. D., Vig, E. K., Back, A. L. & Curtis, J. R. (2008) Transitions regarding palliative and end-of-life care in severe chronic obstructive pulmonary disease or advanced cancer: themes identified by patients, families, and clinicians. *J Palliat Med*, 11 (4): 601-609.

Ribeiro, O., Paúl, C. & Nogueira, C. (2007) Real men, real husbands: Caregiving and masculinities in later life. *Journal of Aging Studies*, 21 (4): 302-313.

Ritchie, J. & Lewis, J. (2003) *Qualitative Research Practice*. Los Angeles: Sage.

- Robinson, C., Bottorff, J., Pesut, B., Olliffe, J. & Tomlinson, J. M. (2014) The Male Face of Caregiving: A Scoping Review of Men Caring for a Person With Dementia. *American Journal of Men's Health*, 8 (5): 409-426.
- Robinson, L., Clare, L. & Evans, K. (2005) Making sense of dementia and adjusting to loss: psychological reactions to a diagnosis of dementia in couples. *Aging Ment Health*, 9 (4): 337-347.
- Robinson-Whelen, S., Tada, Y., MacCallum, R. C., McGuire, L. & Kiecolt-Glaser, J. K. (2001) Long-term caregiving: What happens when it ends? *Journal of Abnormal Psychology*, 110 (4): 573-584.
- Robison, J., Fortinsky, R., Kleppinger, A., Shugrue, N. & Porter, M. (2009) A broader view of family caregiving: effects of caregiving and caregiver conditions on depressive symptoms, health, work, and social isolation. *J Gerontol B Psychol Sci Soc Sci*, 64 (6): 788-798.
- Rokach, A., Matalon, R., Safarov, A. & Bercovitch, M. (2007) The dying, those who care for them, and how they cope with loneliness. *Am J Hosp Palliat Care*, 24 (5): 399-407.
- Rollero, C. (2016) The Experience of Men Caring for a Partner With Multiple Sclerosis. *J Nurs Scholarsh*, 48 (5): 482-489.
- Rose, J., Redsell, S. & Akister, J. (2017) Do families with mental ill health have a 'voice'? Gatekeeping in health and social care research. *Parental Mental Health and Child Welfare Work*, 2 35-38.
- Rose, N. (1998) *Inventing ourselves Psychology, power, and personhood*. Cambridge: Cambridge University Press.
- Round, J., Jones, L. & Morris, S. (2015) Estimating the cost of caring for people with cancer at the end of life: A modelling study. *Palliat Med*, 29 (10): 899-907.
- Rowland, C., Hanratty, B., Pilling, M., van den Berg, B. & Grande, G. (2017) The contributions of family care-givers at end of life: A national post-bereavement census survey of cancer carers' hours of care and expenditures. *Palliat Med*, 31 (4): 346-355.
- Russell, R. (2001) In sickness and in health. A qualitative study of elderly men who care for wives with dementia. *Aging Studies*, 15 351-367.
- Russell, R. (2016) The Work of Elderly Men Caregivers. *Men and Masculinities*, 9 (3): 298-314.
- Sanders, S., Butcher, H. K., Swails, P. & Power, J. (2009) Portraits of caregivers of end-stage dementia patients receiving hospice care. *Death Stud*, 33 (6): 521-556.

- Sanders, S. & Power, J. (2009) Roles, Responsibilities, and Relationships among Older Husbands Caring for Wives with Progressive Dementia and other chronic Conditions. *Health and Social Work*, 34 (1): 41-51.
- Schlossberg, N. K. (1981) A Model for Analyzing Human Adaptation to Transition. *The Counseling Psychologist*, 9 (2): 2-18.
- Seale, C. & Charteris-Black, J. (2008) The Interaction of Class and Gender in Illness Narratives. *Sociology*, 42 (3): 453-469.
- Shanley, C., Russell, C., Middleton, H. & Simpson-Young, V. (2011) Living through end-stage dementia: The experiences and expressed needs of family carers. *Dementia*, 10 (3): 325-340.
- Shaw, R. (2010) Embedding Reflexivity Within Experiential Qualitative Psychology. *Qualitative Research in Psychology*, 7 (3): 233-243.
- Shaw, R. L. (2011) The future's bright: celebrating its achievements and preparing for the challenges ahead in IPA research. *Health Psychology Review*, 5 (1): 28-33.
- Sherman, C. W. & Boss, P. (2007) Spousal dementia caregiving in the context of late-life remarriage. *Dementia*, 6 (2): 245-270.
- Shim, B., Barroso, J. & Davis, L. L. (2012) A comparative qualitative analysis of stories of spousal caregivers of people with dementia: Negative, ambivalent, and positive experiences. *International Journal of Nursing Studies*, 49 (2): 220-229.
- Skinner, B. F. (1987) Whatever Happened to Psychology as the Science of Behaviour? *American Psychologist*, 42 (8): 780-786.
- Smith, J. & Osborn, M. (2007) Interpretive Phenomenological Analysis. *Qualitative Psychology*, (Chapter 4): 53-80.
- Smith, J. A. (2007) Hermeneutics, human sciences and health: linking theory and practice. *International Journal of Qualitative Studies on Health and Well-being*, 2 (1): 3-11.
- Smith, J. A. (2011) Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review*, 5 (1): 9-27.
- Smith, J. A., Flowers, P. & Larkin, M. (2009) Interpretative Phenomenological Analysis: Theory, Method and Research. *Qualitative Research in Psychology*, 6 (4): 346-347.

Smith, J. A. & Rhodes, J. E. (2015) Being depleted and being shaken: An interpretative phenomenological analysis of the experiential features of a first episode of depression. *Psychol Psychother*, 88 (2): 197-209.

Social Care Institute for Excellence-National Institute for Health and Clinical Excellence (2007) Dementia. NICE-SCIE Guideline on supporting people with dementia and their carers in health and social care.

Spiers, J. & Smith, J. (2012) Using Autobiographical Poetry As Data To Investigate The Experience of Living With End-Stage Renal Disease. *Creative Approaches To Research*, 5 (2): 119-137.

Starks, H. & Trinidad, S. (2007) Choose Your Method: A Comparison of Phenomenology, Discourse Analysis, and Grounded Theory. *Qual Health Res*, 17 (10): 1372-1380.

Stevens, A. (1994) *Jung. A Very Short Introduction*. Oxford Oxford University Press.

Stewart, M., Barnfather, A., Neufeld, A., Warren, S., Letourneau, N. & Liu, L. (2006) Accessible support for family caregivers of seniors with chronic conditions: from isolation to inclusion. *Canadian Journal on Aging*, 25 (2): 179-192.

Tannenbaum, C. & Frank, B. (2011) Masculinity and health in late life men. *Am J Mens Health*, 5 (3): 243-254.

Thoits, P. A. (2011) Mechanisms linking social ties and support to physical and mental health. *J Health Soc Behav*, 52 (2): 145-161.

Tilvis, R. S., Routasalo, P., Karppinen, H., Strandberg, T. E., Kautiainen, H. & Pitkala, K. H. (2012) Social isolation, social activity and loneliness as survival indicators in old age; a nationwide survey with a 7-year follow-up. *European Geriatric Medicine*, 3 (1): 18-22.

Tomaszewski, W. & Barnes, M. (2008) Investigating the dynamics of social detachment in older age. *English Longitudinal Study of Aging*, Chapter 5

van der Horst, M. & Coffe, H. (2012) How Friendship Network Characteristics Influence Subjective Well-Being. *Soc Indic Res*, 107 (3): 509-529.

van der Steen, J. T., Gijsberts, M. J., Knol, D. L., Deliens, L. & Muller, M. T. (2009) Ratings of symptoms and comfort in dementia patients at the end of life: comparison of nurses and families. *Palliat Med*, 23 (4): 317-324.

Vargheese, J. P., Sripada, S., Masthoff, J. & Oren, N. (2016) Persuasive Strategies for Encouraging Social Interaction for Older Adults. *International Journal of Human-Computer Interaction*, 32 (3): 190-214.

- Victor, C. R. & Bowling, A. (2012) A longitudinal analysis of loneliness among older people in Great Britain. *J Psychol*, 146 (3): 313-331.
- Victor, C. R., Scambler, S. J., Shah, S., Cook, D. G., Harris, T., Rink, E. & De Wilde, S. (2002) Has loneliness amongst older people increased? An investigation into variations between cohorts. *Ageing and Society*, 22 (05): 585-597.
- Victor, C. R. & Yang, K. (2012) The prevalence of loneliness among adults: a case study of the United Kingdom. *J Psychol*, 146 (1-2): 85-104.
- Vilardaga, R., Hayes, S. C. & Levin, M. E. (2009) Creating a Strategy for Progress: A Contextual Behavioural Science Approach. *The Behaviour Analyst*, 32 105-133.
- Wawrziczny, E., Antoine, P., Ducharme, F., Kergoat, M. J. & Pasquier, F. (2016) Couples' experiences with early-onset dementia: An interpretative phenomenological analysis of dyadic dynamics. *Dementia (London)*, 15 (5): 1082-1099.
- Wenger, L. M. (2011) Beyond Ballistics: Expanding Our Conceptualization of Men's Health-Related Help Seeking. *American Journal of Men's Health*, 5 (6): 488-499.
- Whitney, S. N., McGuire, A. & McCollough, L. (2003) A Typology of Shared Decision Making, Informed Consent, and Simple Consent. *Annals of Internal Medicine*, 140 (1): 54-59.
- Windle, K., Francis, J. & Coomber, C. (2011) Preventing loneliness and social isolation :interventions and outcomes. *Social care institute for excellence*, (October):
- Wood, W. & Eagly, A. H. (2015) Two Traditions of Research on Gender Identity. *Sex Roles*, 73 (11-12): 461-473.
- World Health Organisation (2012) For carers of people with dementia produce benefits/harm in the specified outcomes
- Youell, J., Callaghan, J. E. M. & Buchanan, K. (2016) "I dont know if you want to know this": carers understandings of intimacy in long term relationships when one partner has dementia. . *Ageing and Society*, 36 946-967.

Appendices

Appendix 1 Systematic Review

Author, Date & Country	Study Design	Sample Population	Data Collection.	Data Analysis	Main Themes/ Findings
Boland and Sims 1996 USA.	Grounded theory.	17 families studied caring for those aged 14months to 87yrs. 14 out of 17 carers women.	Interviews conducted in the home. No information as to how many. Interviews recorded and transcribed.	Analysis achieved by constant comparison. Categories were then grouped and incorporated into subsequent interviews.	Core theme was caregiving as a solitary journey with burden, responsibility, isolation and commitment shaping the journey.
Albinsson and Strang 2003 USA.	Qualitative Study.	20 family caregivers from 2 nursing homes, 1 day centre, and 1 private group dwelling for those with dementia. 50% carers female.	Individual interviews 1hr.	Data interpreted using a hermeneutic approach.	Freedom. Isolation. Death. Meaninglessness.
Proot et al 2003 Netherlands.	Grounded theory study.	13 family caregivers of those with a terminal disease at home. 2 carers men 11 carers women. Mean age 51yrs. 9 spousal carers 4 adult children	Semi structured interviews. Interviews lasted 40-120 minutes. In 4 interviews partner present. In 1 interview a friend was present.	Data analysed by constant comparative method as used in grounded theory. Data and investigator triangulation was used to increase validity of findings.	Carer vulnerability core category encompassing, Care burden, fear restricted activities, insecurity, loneliness, facing death, lack of information, lack of emotional and practical support.

Cain et al 2004 Canada.	Qualitative study.	42 carers of those with cancer, those dying or have died of cancer, those with HIV related illness and those with later life illness. No demographic info.	Focus group discussion. 4 individual interviews. Audio-taped sessions later transcribed and analysed.	Themes across focus groups and interviews were devised. Little evidence of how in research paper.	Overwhelming demands of providing care. Social isolation as a direct result of caring. Difficulty of negotiating care system, and financial cost of home care for families.
Rokach et al 2007 Canada.	Grounded theory design.	37 cancer pts, 78 family caregivers, 128 participants/general public. Across sample 74men 169 women. 97% spousal carers 3% adult children carers.	Individual interviews 1hr. Loneliness questionnaire. 34 item 10% declined to participate.	Data interpreted using a hermeneutic approach. Anonymous answers. MANCOVA and ANCOVA measures used for analysis of data.	Freedom. Isolation. Death Meaninglessness. Different research groups coped differently with experience of loneliness.
Sherman and Boss 2007. USA.	Qualitative study. Grounded theory.	9 late-life remarried wife caregivers of those with dementia. Mean age of carers 62yrs.	Individual in-depth interviews. 1.5-2hrs.	Family systems theory provided theoretical framework for study. Also grounded theory approach to data analysis.	Increased isolation due to complex stepfamily dynamics. Rejection of remarriage by adult children. Desertion in the caregiving role. Conflict in caregiving.

Carter et al 2010 Canada.	Qualitative study.	<p>19 family caregivers of those with advanced prostate cancer.</p> <p>15 wives, 3 daughters and 1 son.</p> <p>95% carers' women. Mean age spousal carers 71yrs Mean age adult children 56yrs.</p>	<p>Semi-structured interviews lasting 40-90mins. Focus group 60-90mins.</p>	<p>Interview guide was the same for the interviews and focus group discussion.</p> <p>Data analysed concurrently with collection. NVIVO software used to correlate themes. Data collection stopped at saturation point.</p>	<p>Carer need for information. Uncertainty about the future.</p> <p>Carers for those with hormone-refractory cancer and chemotherapy treatment identified caregiver burden, practical assistance and isolation.</p>
Duggelby et al 2011 Canada.	Qualitative study.	<p>6 patients and 10 bereaved caregivers of those with cancer.</p> <p>Focus groups consisted of 12 professionals Carers mean age 62yr 8 female carers 2 male carers.</p>	<p>Individual telephone interviews taped and analysed.</p>	<p>Open ended interview schedule.</p> <p>Adaption of schedule based on responses for second interview.</p>	<p>Community connectedness/isolation.</p> <p>Lack of accessibility to care.</p> <p>Communication and information issues.</p> <p>Independence/dependence.</p>

Shanley et al 2011 Australia.	Qualitative study.	15 family carers of those with end stage dementia. Mean age carers 64yrs. Mean age adult children carers 48. 8 out of 15 carers female.	Purposive sampling. 1 hr semi structured interviews.	Initial themes identified from interviews. Second grouping of themes across all interviews.	5 main themes Getting support. Having to trust others with care. Managing loneliness. Witnessing a love one fade away. Anticipating and experiencing death.
McHugh et al 2012. Ireland.	Grounded theory	14 family caregivers of those with dementia All carers were spousal carers. 8 of 14 were male 6 were female.	Semi-structured interviews.	Grounded theory analysis.	Main themes, Support needs. Social isolation. Patient-caregiver relationship. To develop relevant ICT.
Beeson et al 2000 USA.	Secondary analysis of quantitative data.	242 carers of those with dementia. 35% carers husbands 52% carers wives 32% carers daughters Mean age 72yrs husbands and wives Mean age 52yr daughters.	Hypotheses testing.	Measures examined, Depression scale reporting. Loneliness scale. Relational deprivation score.	Loneliness significantly related to depression in carers. Loneliness effected current quality of relationships in caring. Loneliness was the only variable to reliably predict depression in carers of those with dementia.

Robinson-Whelan et al 2001 USA.	Longitudinal study 4yrs.	49 former caregivers, 42 continuing caregivers of those with dementia, 52 non-caregiving adults. 64% women. Mean age of carer groups 70yrs.	Self-report questionnaires annually. Series of annual interviews.	5 measures of psychological well-being were analysed using repeated variance measures. 5 measures were, Depression, loneliness affect, stress and well-being.	Feelings of depression, loneliness and poor positive affect remained with the carer for up to 3yrs after caring ends. Consequences of long term caring are long term for carers.
Mathews et al 2003 USA.	Quantitative cross-sectional study.	152 family carers of cancer survivors. Mean age 56yrs. 53% carers female 47% carers male 66% carers wives 83% couples married.	20 page self-report questionnaire. Sections on expectancies, behaviour, emotional strain, and quality of life.	T-test and chi-square analysis was performed.	Health stance and emotional strain were not linked. Both aspects eg. isolation contribute significantly to QOL experiences. More area specific research needed.
Andren and Elmstahl 2005 Sweden.	Cross sectional investigation design.	130 family caregivers of those with dementia. Mean age carers 61yrs. 74% carers women 20% carers spouses.	Questionnaires including caregiver burden scale, Nottingham health profile, sense of coherence scale and the Euroqol instrument.	Kolmogorov-Smirnov test, Spearman rank-order correlation, Mann-Whitney U-test, and Kruskal-Wallis test.	Caregivers experienced moderate caring burden. Strong association between burden, isolation, disappointment, sense of coherence and perceived health scores of carers' experience.

Droes et al 2006 Netherlands.	Quasi-experimental design.	71 carers from MCSP centres. 13 carers of dementia pts. From 3 psychogeriatric day care centre. Mean age MCSP 64yr Mean age DC 60yrs 90% careers female across groups. 90% couples married.	Initial General Health Questionnaire, Sense of Competence scale, Jalowiec Coping Scale, Social Support List, Loneliness Scale and NeuroPsychiatric Inventory. Carer interviews.	Kruskal-Wallis test, mean and standard deviation tests, t-tests and univariate covariance analysis of data.	Those attending the MSCP groups felt less burden. Attending the MSCP group delayed pt admission to nursing homes. Married or cohabiting carers experience improved psychological and psychosomatic symptoms.
Stewart et al 2006. Canada.	Intervention process research. Intervention-telephone peer support.	66 family caregivers. Two groups of carers for those with a stroke or Alzheimer's disease. Mean age 60yrs. 59% spouses, 36% sons and daughters, 5% siblings. 66% of population female. 83% of population married.	Telephone sessions audiotaped and transcribed. Field notes. Pre, post and delayed post- test qualitative interviews taped and transcribed. Exit interviews taped and transcribed. Tele-conference meetings of project staff, peers and professionals taped and transcribed.	Inductive analysis evidence. Framework for coding developed by investigators. Concepts defined and linkages made. Themes devised. NUD*IST used for data analysis.	Decreased support needed for caregivers. Increased support satisfaction. Increased feelings of competence/confidence. Reduced feelings of loneliness. Reduced caregiver burden. Improved coping.

Bramble et al 2008 Australia.	Descriptive qualitative design. Part of a mixed method sequential design study.	10 family caregivers of those with dementia in a care home. 7 out of 10 carers female. No information for age demographics.	Semi-structured interviews. 1hr in length. Carers interviewed in their own home.	Confirmatory thematic analysis. Codes across interviews then narrowed following reflection and discussion within research team.	Increasing burden and isolation prior to admission. Relentless grief. Seeking connection and meaning with staff. Looking after the person.
Sanders et al 2008 USA.	Mixed-method descriptive study.	44 family caregivers of those with Alzheimer's disease and related dementia ADRD. 83% of carers female 53% carers spouses 48% adult children most daughters. Mean age of carers 65yr.	Questionnaires followed by interviews. Spouses were interviewed in own homes. Adult children interviewed by telephone.	Qualitative interviews analysed by open and line by line coding. Constant comparative method used to merge themes. Triangulation of data conducted to ensure consistency/reliability. Quantitative phase of study reported by Ott et al in press.	7 themes from interviews Yearning for the past, Regret and grief, Isolation, Restricted freedom, Life stressors, Systemic issues, Coping strategies. These themes consistent with high carer grief levels. Carers would benefit from supportive interventions to reduce isolation, lack of freedom and regret and grief.

Robison et al 2009 USA.	<p>Quantitative study.</p> <p>Hypotheses:</p> <p>Caregivers report worse health or psychosocial outcomes compared with non-caregivers.</p> <p>Caregivers with particular characteristics or facing more stressful conditions of caregiving will exhibit poorer health and psychosocial outcomes.</p>	<p>2,761 surveys from randomised mailing of residents.</p> <p>Further distribution in Connecticut received 764 surveys.</p> <p>Interested general public generated 1,175 surveys.</p> <p>Respondents younger than 42yrs were excluded.</p> <p>Total sample 4,041</p> <p>Mean age 71yrs.</p> <p>59% sample women.</p>	<p>12 page survey booklet.</p> <p>Prime-MD 2 question depression symptom screen.</p> <p>Self-rating health score adapted from Medical Outcomes Study(1992-1994).</p> <p>Behavioral Risk Factor Surveillance System Survey Questionnaire (BRFSS 1999).</p>	<p>1st hypothesis tested by Pearson chi-square test.</p> <p>2nd hypothesis tested by using logistic regression testing of 6 health and social outcome measures.</p>	<p>1st hypothesis was not supported, caregivers reported overall improved health.</p> <p>No difference was seen in depressive symptoms between caregivers and non-caregivers.</p> <p>2nd hypothesis was also not supported with the limited findings of this study suggesting that further research is needed into the long term effects of caring.</p>
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Leggett et al 2010 USA.	Internet survey.	<p>611 current family caregivers of those with Lewy Body Dementia.</p> <p>36% carers wives 6% husbands.</p> <p>87% carers women.</p> <p>Mean carer age 56yrs.</p> <p>68% couples married.</p>	<p>Questionnaires.</p> <p>Behavioural and emotional problem scales.</p> <p>ADL'S and Mobility scales,</p> <p>Isolation question.</p> <p>Access services questionnaire</p> <p>Evaluation of help.</p>	<p>Axis factor analysis.</p> <p>Multiple linear regression to establish relationships of stresors.</p>	<p>Carer burden 3 dimensions</p> <p>Role strain</p> <p>Personal strain</p> <p>Performance worry.</p>
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Appendix 2 Ethics Letter Pilot Study

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru

T:\ETHICS\CORRESPONDENCE\2014 correspondence\AYoung(SL14)(PR)13-01-14.rtf
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13 January 2014

Professor Annie Young
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CV4 7AL

Dear Professor Young

Study title: How effective are audio diaries for exploring informal male carer experiences of changing social and personal relationships?. A pilot study.

REC reference: 13/WA/0412
IRAS project ID: 137008

Thank you for your correspondence dated 10 January 2014, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Ms Penny Beresford, penny.beresford@wales.nhs.uk.


Confirmation of ethical opinion


On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Cynhelir Cydweithrediad Gwyddor Iechyd Academaidd y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd gan Fwrdd Addysgu Iechyd Powys
The National Institute for Social Care and Health Research Academic Health Science
Collaboration is hosted by Powys Teaching Health Board

 **GIG Cymru NHS Wales** | Bwrdd Iechyd Addysgu Powys
Powys Teaching Health Board

 **Arms of Wales**
Llywodraeth Cymru
Welsh Government

T:\ETHICS\CORRESPONDENCE\2014 correspondence\AYoung(SL14(PR)13-01-14.rtf

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett [REDACTED], the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

T:\ETHICS\CORRESPONDENCE\2014 correspondence\AYoung(SL14(PR)13-01-14.rtf

Approved documents

The documents reviewed and approved by the Committee are:

Document	Version	Date
Evidence of insurance or indemnity	Liability letter	26 July 2013
GP/Consultant Information Sheets : Appendix 4	2.0	10 January 2014
Interview Schedules/Topic Guides: Appendix 5	2.0	10 January 2014
Investigator CV		
Letter from Sponsor	1	20 December 2013
Letter of invitation to participant	1	11 November 2013
Other: CV	Rose Horton-Smith	30 December 2013
Other: Participant Reply Slip : Appendix 3	2.0	10 January 2014
Other: Participant contact numbers : Appendix 6	2.0	10 January 2014
Participant Consent Form: Appendix 2	2.0	10 January 2014
Participant Information Sheet: Appendix 1	2.0	10 January 2014
Protocol	2.0	10 January 2014
REC application	1	
Response to Request for Further Information		10 January 2014

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

T:\ETHICS\CORRESPONDENCE\2014 correspondence\AYoung\SL14(PR)13-01-14.rtf

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

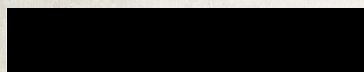
13/WA/0412

Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



Chairman

Email: penny.beresford@wales.nhs.uk

Enclosures: *"After ethical review – guidance for researchers" [SL-AR2]*

Copy to: *Mrs Rose Horton-Smith
Dr Peter Hedges, University of Warwick
Ms Amanda Jones, Worcestershire CRU*

Appendix 3 Pilot Study Information Sheet

How effective are oral diaries for exploring informal carer experiences of changing relationships?

Pilot study Information Sheet for Participants

You are being invited to take part in a pilot study that I am carrying out as a post-graduate student at the University of Warwick. This study is considering the use of oral diary reporting of carers experiences of changing relationship during home care for those with cancer or dementia. Please read this information carefully and discuss with others if you wish. If there are any answers you need before deciding to take part or not please contact me. My contact details are at the end of the sheet.

Thank you for reading this.

PART ONE

What is the study about?

This study is asking carers about their experiences of changing relationships whilst caring for someone with dementia or cancer at the end of their life. Your memories and feelings are very important and will enable us to improve the care those with cancer or dementia receive.

Do I have to take part?

No. It is up to you whether you take part or not. If you decide to participate then you may still withdraw at any time without giving a reason.

What will happen if I agree to take part?

You will be asked to take part in a pilot study on the use of oral diary keeping as a tool for recording your experiences during your caring experience. We will meet before you commence your recordings for me to answer any questions which you have about the study and ask you to sign a consent form. All the information given during your diary entries will be kept confidential and anonymous. No names or identifying features will be used that may identify you.

What do I do now?

If you would like to take part please complete the reply slip enclosed and return it to me in the prepaid envelope. I will then contact you by phone to arrange a time for us to meet in the place of your choosing.

What are the benefits of taking part?

The information you give us will help us to understand the experience you have been through, and may help us to improve care for other patients, carers', and families. This information is valuable if we are to improve the services currently being provided.

What are the disadvantages of taking part?

Keeping an oral dairy record of your experiences may at times be difficult and sensitive. The purpose of this pilot study is to evaluate the effectiveness of this tool for the purposes of research.

Will my involvement in the study be kept confidential?

Yes. Everything which you write will be completely confidential. I will remove anything from the recording that could identify you. Only Professor Annie Young, my supervisor at the University and myself will have access to the information you give me. Any quotes that you give which I include in any reports I write will be anonymous and not identifiable with you.

What will happen to the results of the study?

The results from the pilot study will enable me to evaluate the usefulness of oral diary keeping as a method for future research studies.

PART TWO

What will happen if I don't want to carry on with the study?

If you decide you don't want to carry on with the study you may withdraw at any time without giving a reason and without consequence.

What if there is a problem or I have a complaint?

If you have a concern or a complaint about the conduct of this study you should contact;

Dr Peter Hedges
Director of Research Support Services
University of Warwick
University House
Kirby Corner Road
Coventry
CV48UW
[REDACTED]

Who is providing sponsorship and professional indemnity for the study?

The University of Warwick is the sponsor for this project and provides indemnity for its researchers.

Who has reviewed the study?

The pilot study has been reviewed by Professor Annie Young and Dr V Nanton my academic supervisors at the University of Warwick and the Local NHS Research Ethics Committee. For further information about the study please contact:

Rose Horton-Smith [REDACTED]
Macmillan Palliative Care Nurse Specialist
St. Michaels Hospice
Bartestree
Hereford
HR14HA

Appendix 4 Pilot Study Consent form

Title: How effective are oral diaries for exploring informal carer experiences of changing relationships? (please initial the boxes)

I confirm that I have read the information sheet.

☐

I have had the opportunity to ask questions and have had the explanations needed.

☐

I understand that my participation in this study is voluntary and that I may withdraw at any time.

☐

I understand that the information given during the diary keeping whilst remaining anonymous will be used to inform knowledge and improve clinical practice.

☐

Name.

Signature.

Date.

Rose Horton-Smith.

Signature.

Date.

Appendix 5 Pilot Study Reply Slip.

**Title: How effective are oral diaries for exploring informal carer
experiences of changing relationships?**

Participant Reply Slip

Please could you send this slip back in the envelope supplied if you are happy to take part in the pilot study?

I (Name in Block Capitals),
Would like to take part in the study identified.

Telephone Number.....

If you would like to suggest the best times to call, I will call you when it is convenient for you

The best time to call is

Day(s).....
.....

Time(s).....
.....

Many thanks for your help.

Rose Horton-Smith

Appendix 6 Ethics Letter Main Study

NHS
Health Research Authority
NRES Committee West Midlands - Coventry & Warwickshire
 The Old Chapel
 Royal Standard Place
 Nottingham
 NG1 6FS
 Telephone: 0115 8839697

13 August 2015

Professor Annie Young
 Warwick Medical School
 University of Warwick
 Coventry
 Cheltenham
 Glos
 CV4 7AL

Dear Professor Young,

Study title:	How does caring for someone at home with later stage dementia or advanced cancer affect informal male carer experience of changing social and personal relationships?
REC reference:	15/WM/0181
IRAS project ID:	168741

Thank you for your letter of 7th August 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Ms Rachel Nelson, NRESCommittee.WestMidlands-CoventryandWarwick@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

- 1) The consent form should have an additional point saying 'I agree to take part in the study'.
- 2) The Participant Information Sheet should let the participants know that any travel expenses incurred will be re-imbursed if receipts are provided.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will

be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance declaration]	Version 1	12 May 2015
Interview schedules or topic guides for participants [Appendix 5]	Version 1	10 April 2015
Other [Appendix 5(i)]	Version 1	10 April 2015
Other [Appendix 3]	Version 1	10 April 2015
Other [Appendix 3(i)]	Version 1	10 April 2015
Other [Liability insurance certificate]	Version 1	12 May 2015
Other [Dr Nanton CV]	Version 1	12 May 2015
Other [Appendix (i)]	Version 1	10 April 2015
Other [Appendix 2]	Version 1	10 April 2015
Other [Appendix 2(i)]	Version 1	10 April 2015
Other [Appendix 6]	Version 1	10 April 2015
Other [Appendix 6(i)]	Version 1	10 April 2015
Other [Appendix One (i)]	Version 2	07 August 2015
Other [Appendix One]	Version 2	07 August 2015
Other [Appendix Six (i)]	Version 2	07 August 2015
Other [Appendix Six]	Version 2	07 August 2015
Other [Appendix Two (i)]	Version 2	07 August 2015
Other [Appendix Two]	Version 2	07 August 2015
Other [Study Protocol]	Version 2	07 August 2015
Participant consent form [Appendix 2]	Version 1	10 April 2015
REC Application Form [REC_Form_08052015]		08 May 2015
Summary CV for student [Student CV]	Version 1	12 May 2015

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

15/WM/0181

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely,



Dr Helen Brittain (Chair)
Chair

Email: NRESCcommittee.WestMidlands-CoventryandWarwick@nhs.net

Appendix 7 MaCE Study Consent Form

Study Consent Form

Title: How does caring for someone at home with later stage dementia affect informal male carers experience of social and personal relationships?
(please initial the boxes)

I confirm that I have read the information sheet Version 3.0 16/08/2015

☐

I have had the opportunity to ask questions and have had the explanations needed.

☐

I understand that my participation in this study is voluntary and that I may withdraw at any time.

☐

I understand that the information given during the interview whilst remaining anonymous will be used to inform knowledge and improve clinical practice.

☐

I understand that I will participate in up to three interviews.

☐

I give my consent to the recording of my interview(s)

☐

I agree to take part in the study

☐

Name.

Signature.

Date.

Rose Horton-Smith.

Signature.

Date.

Appendix 8 Interview Schedule- Cancer

Semi-structured interview schedule

Title: Experiences of Social and Personal Relationships

The following questions may be used to guide the discussion during the interview. Some or all of the questions may be used. When asking questions, the term *person* will be substituted by the individuals first name.

Introduction

Thank you for allowing me into your home today to discuss your experience for caring for someone with cancer. I am interested in your experience, the feelings and challenges that are important to you. Please can I clarify that you have read the information sheet provided and have understood the purpose of the interview today?' Have you completed the consent form?

Section One. *Illness and support network*

1.0 Please tell me about *the persons'* cancer? (Duration, trajectory and, treatment).

1.1 What professional help or support do you receive for (e.g. District Nurse, GP, occupational therapist, or professional carers).

1.2 What professional help or support do you receive for yourself? (e.g local carer support groups/ agency or sitting/respite services)

1.3 Please tell me about your friends and family? (Local support, social support for example.)

Section Two. *Emotional Issues.*

2.0 Please tell me what being a carer means to you.

2.1 What is the most rewarding aspect of your role?

2.2 What is the most challenging part of you caring role? How does that make you feel?

2.3 What is the reaction of your family and friends to cancer?

2.4 If you can could you explain to me how your relationships with your friends and family has changed during the time you have been caring for ...

Prompt : How do you feel about that?

2.5 Can you tell me what was the reaction of your family and friends to your new role of carer?

2.6 Do you think they see you differently now?

Prompt : Can you tell me more about that?

2.7 Who do you see or hear most from in a typical week?

Prompt What would you say is the balance of how much contact you have with family/friends/professionals. How has this changed over time if at all?

Section Three.*Closing the Interview*

3.0 Thank you for your time today and for sharing your experiences with me.

3.1 Is there anything else you would like to tell me?

3.2 What would you like to say to professional/other carers about your experience?

Thank you.

This information will be very useful and will help us understand the experiences of male carers in more detail.

Appendix 9 Interview Schedule- Dementia

Semi-structured interview schedule

Title: Experiences of Social and Personal Relationships

The following questions may be used to guide the discussion during the interview. Some or all of the questions may be used. When asking questions the term *person* will be substituted by the individuals first name.

Introduction

'Thank you for allowing me into your home today to discuss your experience for caring for someone with dementia'. 'I am interested in your experience, the feelings and challenges that are important to you'. Please can I clarify that you have read the information sheet provided and have understood the purpose of the interview today?' 'Have you completed the consent form?'

Section One.

Illness and support network

1.0 Please tell me about *the persons'* dementia? (Duration, trajectory and, treatment).

1.1 What professional help or support do you receive for (e.g. District Nurse, GP, occupational therapist, or professional carers).

1.2 What professional help or support do you receive for yourself? (e.g. Alzheimer society, local carer support agency or sitting/respite services)

1.3 Please tell me about your friends and family? (Local support, social support for example.)

Section Two.

Emotional Issues.

2.0 Please tell me what being a carer means to you.

2.1 What is the most rewarding aspect of your role?

2.2 What is the most challenging part of you caring role? How does that make you feel?

2.3 What is the reaction of your family and friends to dementia?

2.4 If you can could you explain to me how your relationships with your friends and family has changed during the time you have been caring for ...

Prompt : How do you feel about that?

2.5 Can you tell me what was the reaction of your family and friends to your new role of carer?

2.6 Do you think they see you differently now?

Prompt :Can you tell me more about that?

2.7 Who do you see or hear most from in a typical week?

Prompt What would you say is the balance of how much contact you have with family/friends/professionals. How has this changed over time if at all?

Section Three.*Closing the Interview*

3.0 Thank you for your time today and for sharing your experiences with me.

3.1 Is there anything else you would like to tell me?

3.2 What would you like to say to professional/other carers about your experience?

Thank you.

This information will be very useful and will help us understand the experiences of male carers in more detail.

Appendix 10 MaCE Information Sheet

How does caring for someone at home with advanced cancer affect informal male carers experience of social and personal relationships?

Study Information Sheet for participants.

You are being invited to take part in a research study that I am carrying out as part of my doctoral (PhD) study at the University of Warwick. This study is considering male carers experiences of relationships with family and friends during home care for those with advanced cancer. Please read this information carefully and discuss with others if you wish. If there are any answers you need before deciding to take part or not please contact me. My contact details are at the end of the sheet.

Thank you for reading this.

PART ONE

What is the study about?

This study is asking male carers about their experiences of relationships whilst caring for someone with advanced cancer. Your memories and feelings are very important and may enable us to improve the care those with cancer receive.

Do I have to take part?

No. It is up to you whether you take part or not. If you decide to participate then you may still withdraw at any time without giving a reason.

What will happen if I agree to take part?

You will be interviewed up to a maximum of three times by me to discuss your experiences during your caring experience. This interview will be recorded and transcribed. All the information given will be kept confidential and anonymous. No names or identifying features will be used that may identify you. Any travel expenses incurred by you during the study will be reimbursed if receipts are provided.

What do I do now?

If you would like to take part please complete the reply slip enclosed and return it to me in the prepaid envelope. I will then contact you by phone to arrange a time for us to meet in the place of your choosing.

What are the benefits of taking part?

The information you give us will help us to understand the experience you have been through, and may help us to improve care for other patients, carers', and families. This information is valuable if we are to improve the services currently being provided.

What are the disadvantages of taking part?

Being interviewed about your experiences may at times be difficult and touch on sensitive issues. The purpose of this study is to understand your experience for the purposes of research. You may like to have a friend or member of your family present during or after the interview(s) to support you. An additional sheet detailing contact numbers and agencies that provide support for carers is included with this sheet.

Will my involvement in the study be kept confidential?

Yes. Everything you say will be completely confidential. I will remove anything from the recording that could identify you. Only Professor Annie Young, my supervisor at the University and myself will have access to the information you give me. Any quotes that you give which I include in any reports I write will be anonymous and not identifiable with you. However, should you tell me something about your experience that is harmful to either yourself or who you are caring for, then I will discuss with you the implications of this and may need to alert others for support.

What will happen to the results of the study?

At the end of the interview(s) you will have the opportunity to ask questions you may have or raise any concerns. The results of the study may be used to improve services and support that those caring for someone with cancer receive where needed.

PART TWO*What will happen if I don't want to carry on with the study?*

If you decide you don't want to carry on with the study you may withdraw at any time without giving a reason and without consequence.

What if there is a problem or I have a complaint?

If you have a concern or a complaint about the conduct of this study you should contact;

Dr Peter Hedges
Director of Research Support Services
University of Warwick
University House
Kirby Corner Road
Coventry
CV48UW
02476 523716

Who is providing sponsorship and professional indemnity for the study?

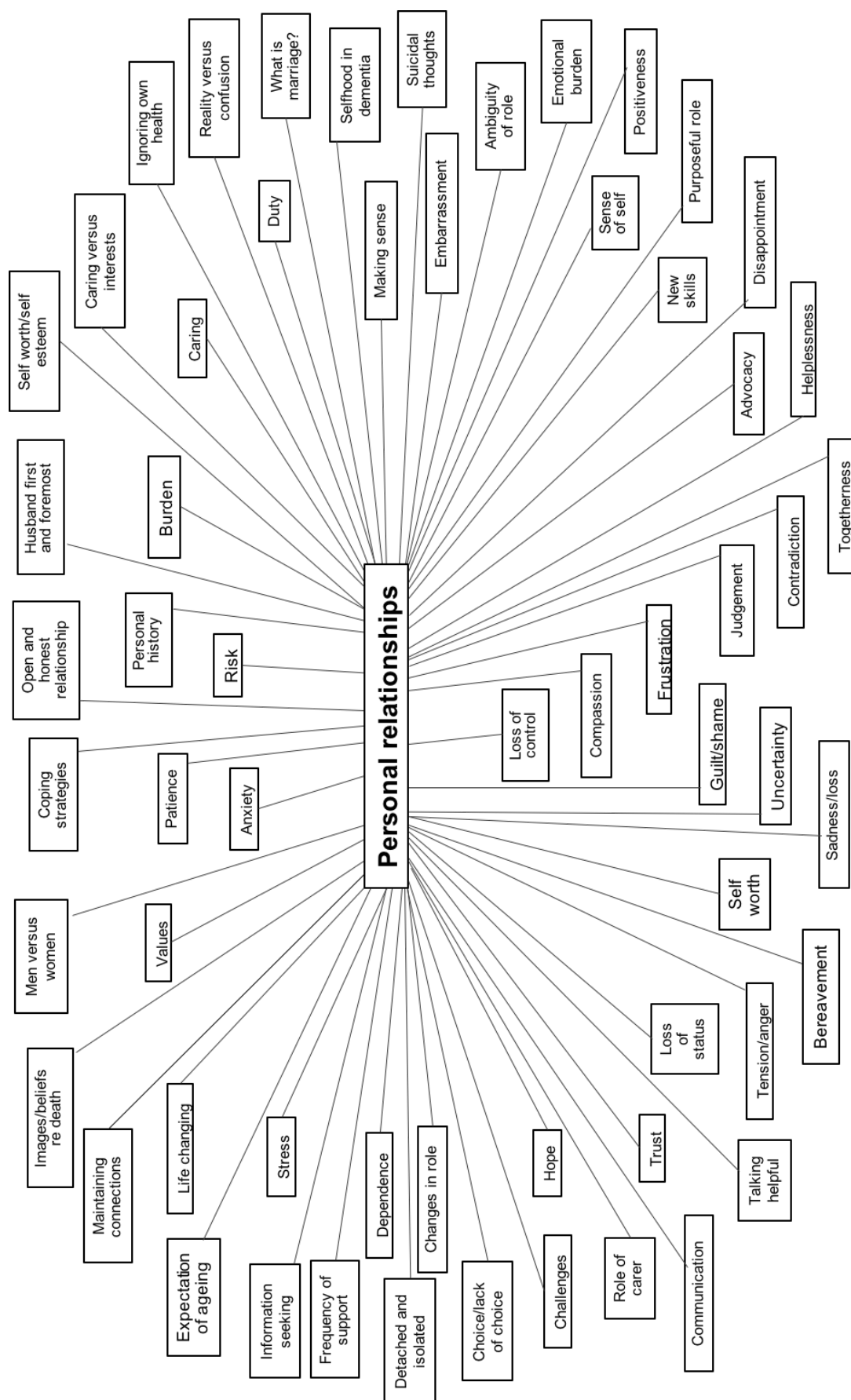
The University of Warwick is the sponsor for this project and provides indemnity for its researchers.

Who has reviewed the study?

The study has been reviewed by Professor Annie Young and Dr V Nanton my academic supervisors at the University of Warwick and the Local NHS Research Ethics Committee. For further information about the study please contact:

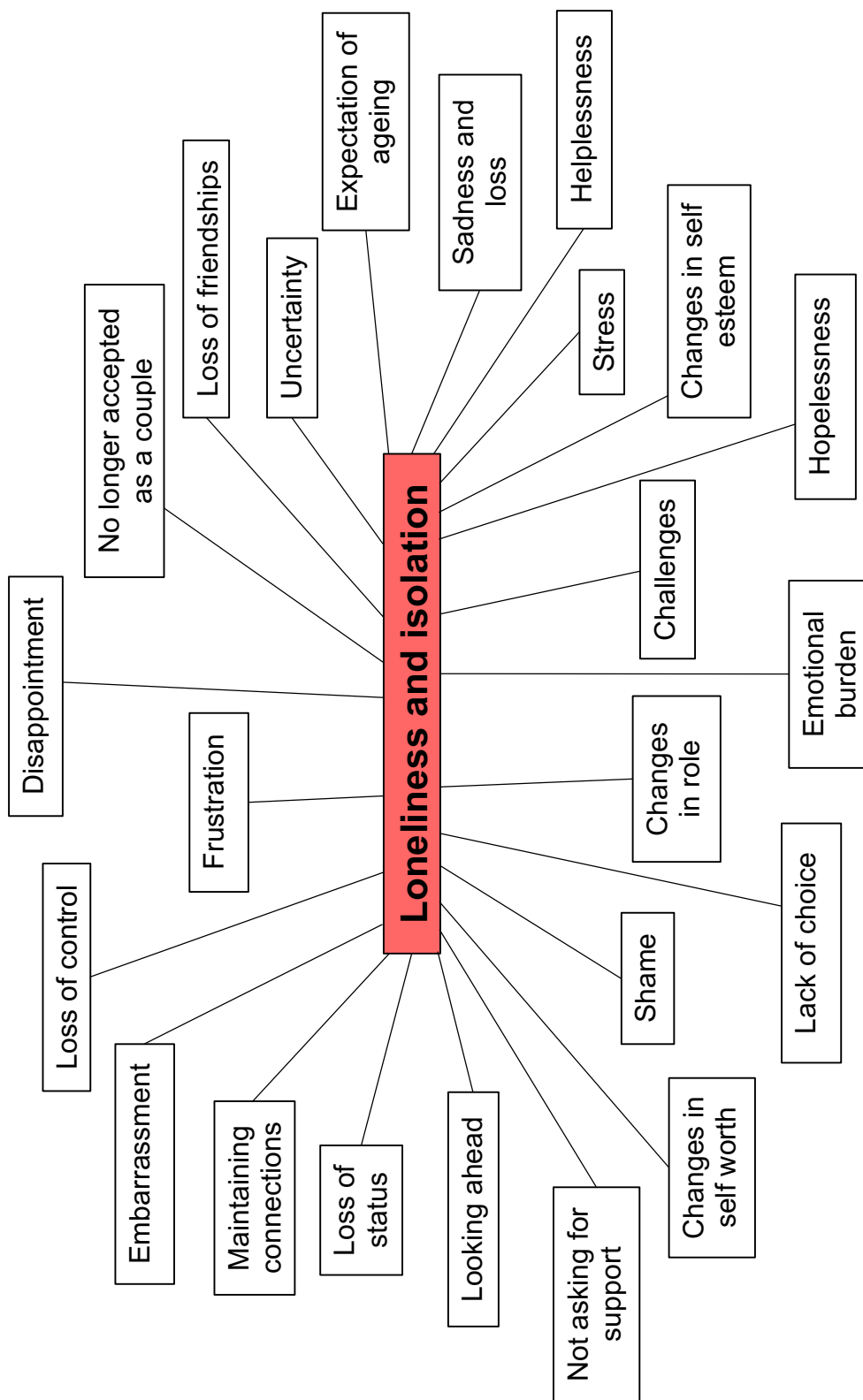
Rose Horton-Smith
Macmillan Palliative Care Nurse Specialist
St. Michaels Hospice
Bartestree
Hereford
HR14HA



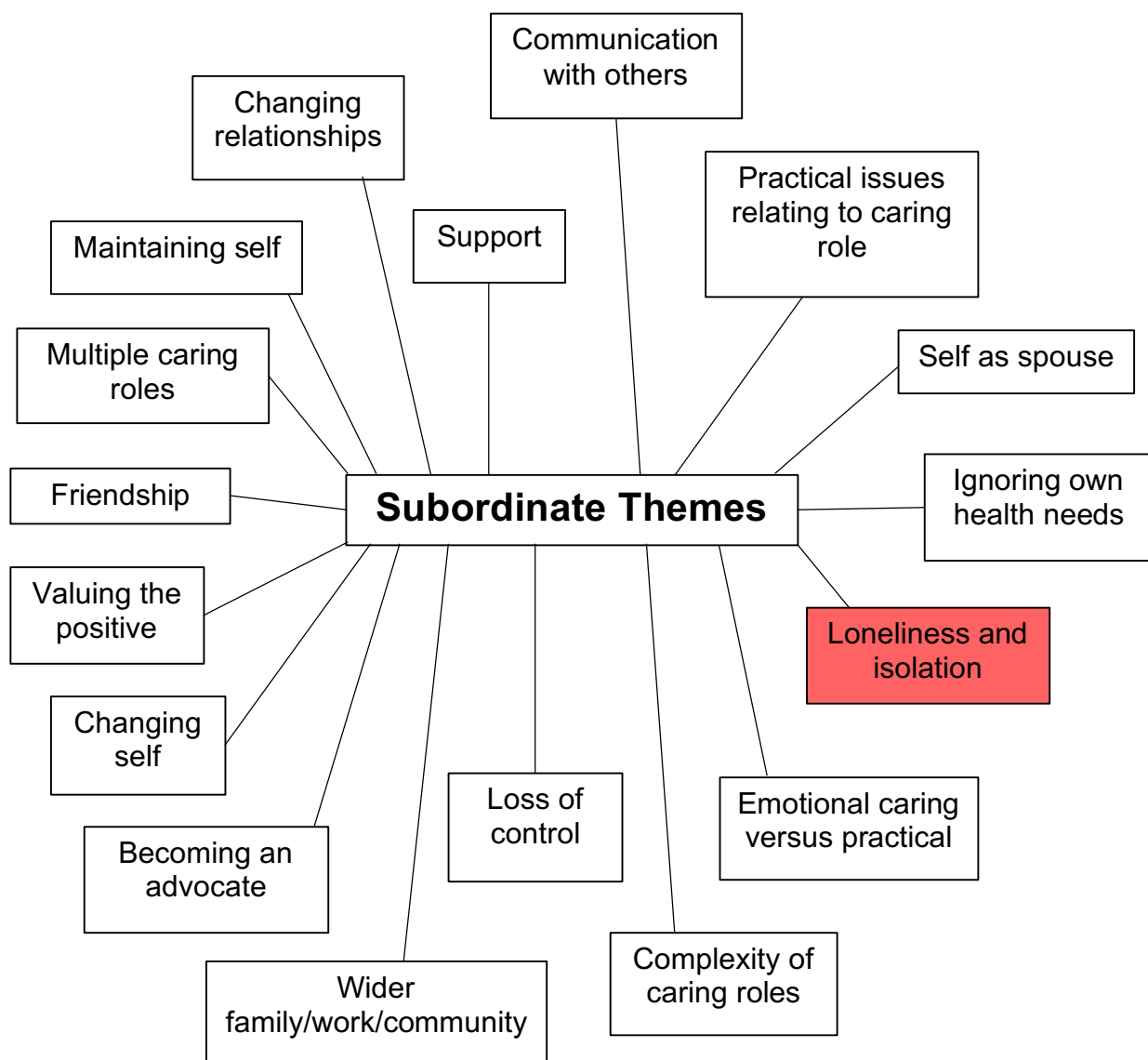


Appendix 12 Example of Emerging Themes

Emerging themes that make up a subordinate theme



Appendix 13 Subordinate Themes



Appendix 14 Superordinate Themes

Subordinate themes leading to superordinate themes

